ABSTRACT

Title of Dissertation. LIFE STORIES AND LIFE STRATEGIES OF PARENTS AND THEIR CHILDREN WITH DYSLEXIA

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Learning to read is an essential life skill. Recent Educational policy initiatives at the national level have emphasized the importance of reading as an essential life skill in American Society.

The No Child Left Behind (NCLB) Act of 2001 states the commitment of President Bush to ensuring that every child in the United States of America can read by the end of third grade. Thus, this act has the potential to impact one of the three groups in the elementary-aged learning to read population. The group who struggles to learn to read will have difficulty becoming literate. The child who struggles

to learn to read may be identified as possibly having a condition that is described in the literature as dyslexia.

Dyslexia is often a misunderstood, misdiagnosed secret shame for those individuals who are identified with this condition. The impact of this diagnosis on the individual as well as their families causes much confusion among these individuals as well as among all of the scientific fields (educational, medical and psychological) dedicated to helping the child and their family.

First person accounts of how elementary-aged children and their families accommodate for their child's dyslexia need to be given a voice in all of the scientific communities that study dyslexia. Recording and researching the daily life experiences will open the door to view the many struggles that these children face. The children's understanding of their dyslexia and the accommodations the children and their families make for the dyslexia is an important missing area in the literature.

Providing an outlet for these missing voices should encourage better communication among all the professions

especially interested in the study of dyslexia. Then, living daily with dyslexia can be more readily understood and will not forever remain a hidden, shadowy, and often misunderstood, secret shame.

LIFE STORIES AND LIFE STRATEGIES OF PARENTS AND THEIR CHILDREN WITH DYSLEXIA

by

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DEDICATION

I would like to dedicate this dissertation to Dr. Joan Lieber at the University of Maryland without whose helpful guidance, thoughtful comments and support helped to make this dissertation possible.

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Chapter 1

Introduction

The ability to read is an essential life skill. Recent educational policy initiatives at the national level have emphasized the importance of reading as an essential life skill in American society. A federal mandate, the landmark No Child Left Behind Act of 2001 was signed into law by the 43rd President of the United States, George W. Bush. This educational reform reauthorizes the Elementary and Secondary Education Act of 1965 and states President Bush's unequivocal commitment to ensuring that every child in the United States of America can read by the end of third grade.

To accomplish this goal, the new Reading First initiative would significantly increase the Federal investment of money to local school district to fund scientifically based reading instruction programs in the early grades of elementary school. (http://www.ed.gov/print/nclb/overview/intro/execsumm.html) Thus, the No Child Left Behind (NCLB) Act has the potential to impact one of the three distinct groups of children in

the learning to read population.

One group is that population of early elementary-aged children who have seemingly little difficulty acquiring the skills related to learning to read. These children have entered their schooling experience already possessing ownership over those skills that are needed for reading. Another group of early elementary aged children are entering their school experience not quite at ease with the printed word, but ready to acquire those reading skills that are taught to them. By all accounts, the children from these two groups are on their way to becoming literate.

However, in the midst of these groups of children who are at apparent ease working with letters and sounds, are a group of children who experience a struggle when attempting to read or write. Such struggles can cause an upheaval and interfere with the process of becoming literate. This disruption in the child's school progress has an impact not only on the child, but also upon members of the child's family. The struggle to read then, targets the children in this latter group.

The children of this third group are often unofficially identified as having “something wrong with them” that made them different from their peers in acquiring the necessary skills to be able to read. The “something” that appears wrong or different may identify the child as possibly having a condition that is described in the literature as dyslexia.

Dyslexia: An Overview

The definition of dyslexia listed on the International Dyslexia Association’s web site (http://www.interdys.org) is the following:

> Dyslexia is a specific learning disability that is neurological in origin. It is characterized by difficulties with accurate and/or fluent word recognition abilities and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading

experience that can impede growth of vocabulary and background knowledge. (http://www.interdys.org)

A conservative percentage of persons with a language based learning disability in the general U.S. population is approximately “15-20% of the population.” (http.//www.interdys.org.)

Many people with a language-based learning disability, usually referred to in the literature as dyslexia, may appear to be bright. (Smith,1995). They may have intelligence that appears to be above average and perhaps even appear quite gifted in certain arenas such as music, art or physical skills.

Several studies in the last twenty-five years have compared populations of readers with dyslexia (sometimes called "poor") and good readers on the above three dimensions. For example, Brandy, Mann & Schmidt (1987) found that the technical acquisition of specific reading sub-skills such as sound (phoneme) symbol-(letter) decoding, language, and comprehension were present in good reader as apposed to poor readers; while Wagner & Torgesen (1987)

studied metaphonological difficulties experienced by efficient and inefficient readers in the phonological process and found that metaphonological difficulties caused inefficient readers to have more difficulty with comprehension than efficient readers.

Study Rationale

However, one of the major problems in the research literature on dyslexia is summarized in Gillet & Temple's 1990 observation that "dyslexia is a condition that everyone seems to agree exists, but about which there is little agreement otherwise". (Gillet & Temple, as quoted in Hennigh 1995,p.2). Moreover, the scientific literature that emphasizes the three major research areas cited above gives comparatively little attention to documenting the actual day-to-day life experiences of the children diagnosed with dyslexia and their families. Examples of day to day life experiences of both children and their families are necessary to understand the complex nature of dyslexia. By using these real life examples, it puts a face on the condition of dyslexia and its effects.

Moreover, the bulk of the academic literature about dyslexia is not readily available to the ordinary person who might need this information (e.g., the parents of a child with dyslexia or the child themselves). Nor is the information available typically free of jargon and confusing technical terminology. Thus, it is often difficult for parents or even classroom teachers to relate the information from the research to the individual circumstances of a particular child.

Likewise, very little information currently exists to provide families with accurate, complete, and specific information to address the concerns of the parents about raising their dyslexic child. The few notable exceptions to this are studies by Donawa (1995), Hartwig (1984), Jones (1992), and Mautner (1984). However, even here, none of these studies interview the children with dyslexia. Rather, these studies were parents' reflections about raising a child with dyslexia. These reflections by the parents were longitudinal in nature and highlighted only a few difficulties faced by parents of the children with dyslexia. Additional studies by Faerstein (1981), Falik (1995) and

Waggoner & Wilgosh (1990) have sought to record the concerns of families and effects of dyslexia on each family. With these studies, however, there is the problem of limited accessibility to the general population. All of these research studies were in academic journals and require some technical background in medicine, education or psychology (or all of these fields) to understand the information.

The present study sought to fill in the gaps of daily life strategies used by children with dyslexia and the parent of these children who were coping daily with dyslexia. This study sought to fill some of the research gaps in the dyslexia literature by recording the following: (a) the personal reflections and daily life strategies used by the parents as they raise their dyslexic child; and (b) the personal reflections and daily life strategies of the children who live daily with dyslexia.

Statement of the Problem

There is little practical information available on the impact that a reading difficulty (often identified or misidentified as dyslexia) has on the family unit. This lack of practical, "nuts and bolts" information is especially

apparent when considering the life strategies used by the children and their family members as they face daily challenges and struggles in academic, social and emotional arenas.

Moreover, each family member's experience in dealing with dyslexia, is something very unique and deeply personal. Each individual family member's experience (child or adult) in dealing with or accommodating for dyslexia is a commitment that lasts a lifetime. The present study focused upon these unique experiences and their impact upon a family's daily life as the cornerstone of its approach.

Significance of the Study

This study will contribute to the literature in three important ways. First, the study will add to the limited available information that exists to help family members acknowledge the effects of dyslexia on a child as well as their parents. Secondly, the study will address the specific effects that a diagnosis of dyslexia has on the members of the child's family. Finally, this study will identify specific compensatory strategies used by the child and family to help the child participate more effectively in

the worlds of home and school.

Research Questions

The two major research questions considered in this study are: (a) What are the experiences, needs, and daily life strategies of parents who have raised or are raising children identified with the specific disability of dyslexia?; and (b) What are the experiences, needs, and daily life strategies of children who have been diagnosed with dyslexia.

Organization of the Study

Chapter 1 introduces the study, provides the study rationale, states the problem and its significance. Also Chapter 1 presents the research questions, and specifies the organization of the study.

Chapter 2 reviews the literature related to children identified with reading difficulties that are often identified as dyslexia. Chapter 2 reviews the literature as it pertains to the individual personal experiences of families with dyslexic children. Chapter 2 also provides operational definitions for the major technical terms used in the study.

Chapter 3 describes the target population, provides the research design, and lists the limitations of the study. Chapter 3 also describes the procedures used to collect and present the data from the interviews as well as the procedures utilized in the data analysis.

Chapter 4 presents the study findings and offers an analysis of the study findings. Chapter 5 provides a discussion of the study findings, explains some of the implications of the study, and gives recommendations for future research.

Chapter 2

Review of the Literature

This chapter contains a review of the research studies related to: (a) the definitions of dyslexia; (b) the diagnosis of dyslexia, (c) remediation approaches; (d) the impact of dyslexia on the child and the members of the child’s family; and (e) the relationships between the parents of the child with dyslexia and the wider school and professional community.

Introduction

Dyslexia is an often misunderstood or misdiagnosed neurological condition. This can mean that children with this condition often remain in the general classroom receiving little or no help or acknowledgement of their problem. As children age and the school workload increases, feelings of inadequacies may surface in the child's mind or in the minds of the family members. An ever-widening gulf will begin to appear between the academic skills of the child with dyslexia and the other children in the classroom. As the school work load increases, the student with dyslexia appears to slide further and further behind his or her

classmates.

The child's difficulty keeping pace with classmates often becomes a perplexing puzzle within the family system. Donawa (1995) comments from her own personal experience of raising a child with dyslexia. "He was affectionate, articulate, and well behaved at home, but friendless at school; the picnics and birthday parties went on without him."(Donawa, 1995,p.327). In a more recent work, Feldman (2000) stated that the parents are usually baffled by the child's poor performance at school and assume that he or she simply isn't trying hard enough.(Feldman, 2000). Parents often hope to find an area where their child with dyslexia does not seem behind the abilities of their classmates. As the children struggle to hunt for a sense of themselves amidst the seen and unseen life roadblocks that having dyslexia presents, it is helpful to have a glimpse into the lives of the children with dyslexia and the parents, family members, and teachers who wish to help them succeed.

Definitions of Dyslexia

The 1991 Merriam Webster’s Collegiate Dictionary (Tenth Edition) defined dyslexia as “a disturbance of the ability

to read.” (Webster, 1991, p.391). A later edition of Webster’s II New College Dictionary, a 2001 edition, defined dyslexia as an “impairment of the ability to read.” (Webster, 2001, p.353.)

Whether dyslexia is identified as a disturbance or impairment, the word "dyslexia" contains only eight letters. However, the educational, psychological, and medical fields that concern themselves with the diagnosis, remediation, and impact of dyslexia are all unable to reach a consensus for a precise definition of this complex condition. This lack of definitional consensus within and among the three fields is part of the problem in this area. Most of the studies conducted in the fields of education, psychology, medicine (especially the field of neurology) have focused on one or more of the following three major research areas:(a) identifying and defining dyslexia as a specific neurological condition, (b) diagnosing dyslexia in children (to a greater extent) and in adults (to a lesser extent), and (c) remediation with educational strategies and resources used to assist children with dyslexia to improve basic academic skills.

Many educational professionals working with children refer to dyslexia superficially as a reading problem. However, in the field of psychology, the home environment is named as a strong indicator of reading success or failure. Therefore, this home environment is seen as a place of possible deprivation in the areas of language, cultural or educational opportunities. These deprivations in the home are seen as contributing to the syndrome of dyslexia.

The medical profession has investigated the syndrome of dyslexia from the viewpoint of its physical, organic, and neurological manifestations. While these three different fields of study are interested in a definition of dyslexia, the definitions range from the simplified to the complex and unwieldy jargon used to identify the multi-complex constellations of dyslexia among individuals, and therefore offer limited guidance to the numerous educational, psychological, and medical field professionals entrusted with the diagnosis and remediation of the disorder of dyslexia. In addition (and important for the context of the present study), such definitions offer little precise information on the impact that dyslexia will have on the

child and the family.

Diagnosing Dyslexia

The most confusing and frustrating difficulty in diagnosing dyslexia is the array of symptoms found in each individual case. Each individual case often represents a different cluster of difficulties. Thus, when comparing several individual cases, the learning difficulties may appear as similar clusters of deficiencies. However, when viewing the cases separately, the learning difficulties within the individuals may appear to be quite diverse.

According to the International Association of Dyslexia's website, learning disabilities have many different names.

> Dyslexia is one type of learning disability. Other learning disabilities include dyscalculia, a mathematical disability in which a person has unusual difficulty solving arithmetic problems and grasping math concepts [and] dysgraphia, a neurological-based writing disability in which a person finds it hard to form letters or write within a defined space. (http://www.interdys.org).

Although symptoms are not present at the same intensity in every single person, there appears to be the common ground of reading difficulties among dyslexic individuals.

Moreover, common problems in certain areas (reading, spelling, language, and math) can be displayed on a continuum. The continuum ranges from the severe to the subtle in their manifestation. The characteristics of dyslexia can appear alone or in a cluster with other characteristics (i.e. problems with attention and concentration), making the diagnosis of dyslexia laborious and at times, subjective. Many of these particular learning difficulties can be found within the general population. Therefore, a diagnosis of dyslexia may be difficult to achieve.

In the field of education, dyslexia may be identified when there appears to be a discrepancy between a child's ability, as measured by an intelligence test, and that child's performance in reading, written language, or mathematics. The many factors that cluster around dyslexia make it essential to have an accurate diagnosis of the problem so that the correct assistance can be given to the

child who is experiencing the learning difficulty.

A child’s teacher may initiate an educational evaluation after that child has been unable to keep pace with his/her peers in the academic, social or organizational aspects of school. The initial questioning of a child's difficulty may appear at any time during the child's lifetime, but the discrepancies in learning usually begin to be recognized by the end of Kindergarten or Grade One.

This discrepancy does not mean that dyslexia cannot result in a learning discrepancy when the child is older, as symptoms of dyslexia can appear at any age. The diagnosis of dyslexia may take years to pin down- especially if the symptoms are subtle and overlapping. Although a child’s classroom teacher usually requests referrals for educational intervention, parents can also refer their children for an educational assessment if they feel that something is negatively impacting their child's progress.

Feldman (2000) cautions that, although most children start to learn to read at age five or six, and that this young age is "too soon to tell if the child has dyslexia, because all children make many mistakes in sounding out and

identifying words." (p.33).

Feldman (2000) further states that reading difficulties are more evident when the child is seven or eight years of age. The reason Feldman gives for the older age to be the touchstone for identifying dyslexia, is that this is "the age at which most children are able to read without help." (Feldman, 2000,p.33). Thus, the children with dyslexia and their families become more consciously aware in the early elementary school years that their child has a differing ability from their peers. This differing ability is the inability to decode words and other printed material, two fundamental skills in a literate society. The parents may worry that such a situation may pose a fearful future scenario for the child.

Remediation Approaches

The complexity of dyslexia requires an accurate diagnosis and realistic remediation plan. When a diagnosis of dyslexia is made, the diagnosis generally refers to a difficulty with reading the printed word. For the person with dyslexia, that means instruction is needed in the area of sound-symbol relationships or phonics instruction.

Although many remediation approaches in the area of sound symbol acquisition have advanced in the last twenty years, the most widely accepted scientifically based remediation approach for dyslexia is the Orton-Gillingham approach. This instructional approach was developed through a collaborative partnership between Dr. Samuel T. Orton, a medical doctor, and psychologist and teacher Anna Gillingham.

The Orton-Gillingham approach can be described as an individualized, systematic, multisensory approach to assist the student with dyslexia to make sense of the sound-symbol relationships on which language is based. Individual letter-sound (phoneme) relationships are isolated and then presented to the child in sequential steps, which increase in complexity. The sound of the individual letters or letter combinations can be blended into words for reading. Practicing these individual sound-symbol relationships allows the child to develop control over the printed symbols that make up the words and sentences, which ultimately convey meaning. Through diligent practice, many dyslexic individuals can become fluent with linguistic code. However,

this does not imply that this is an easy task. This "breaking of the code" will help the dyslexic individual to achieve a level of literacy that would have been unlikely had they not received instruction in the Orton-Gillingham approach.

The Impact of Dyslexia on the Child and the Family Members

A central concern of the present study is the question: How does dyslexia impact the child and the family? Fields (1974) stated that any "condition that disables the child assaults the parent-child relationship..." (in Faserstein, 1981,p.420). Kubler-Ross (1969) and Miller (1986) studied children with chronic illnesses and documented parents' feelings of guilt, shame, danger, blame, and denial.

Although there have been many studies focusing on children with physical disabilities (e.g., chronic illness or mental retardation), there has not been much in depth investigation into how parents of children with learning disabilities have coped with the stress of these disorders. This lack of information about the disorder of dyslexia may cause it to remain a shadowy intrusion in the family dynamic

and may cause confusion and unintentional misinformation from professionals.

If a hidden disability is an intellectual disability rather than a physical disability, the stress on the parents is particularly troublesome. For example, Ferholt & Solnit (1978) discovered that parents were more likely to surmise that they were totally responsible for their child’s problem in cases of a hidden intellectual disability.

This erroneous assumption, according to Arnold (1978) "feeds into the parents' preexisting self blame and the resultant feelings of inadequacy, doubt and guilt, sometimes projected onto the child, [which] complicate the parent-child relationship and fuel the hostility already sparked by the child's mischief." (in Faerstein, 1981,p.422). What are the specific family dynamics, which result because of the identification of a hidden learning disability? Faerstein (1979) investigated the coping and defense mechanisms of mothers of children with learning disabilities and found there was an average lapse of 3.5 years between the child's age when the mother first suspected her child had a problem and the actual age when the diagnosis of a learning

disability was made. The diagnosis, in many cases, served to support the often-unvoiced suspicions of the mother. This feeling of support tended to allow the mother to then seek help for a child.

In more recent literature, Feldman (2000) relates the impact dyslexia has on the child and family members. Feldman gives an account of John, (age 11 when interviewed) who had begun falling behind his peers at grade 3. Although John's earlier developmental benchmarks had been reached at the same time as other children, he had had additional tutoring through grade 4 with minimal improvement in the area of reading and writing. Although both of John's parents were supportive and willing to help, Feldman states that the parents were "frustrated with the amount of time it took for John to complete his work”.(p.49)

As for John's younger brother, an excellent student, was "beginning to resent the amount of time his parents spent helping John with his studies at home." (Feldman, p.49). Thus, report card time became a time of anxiety and stress for all family members.

Stress Within the Family Unit

Learning disabilities, especially dyslexia, tends to run in families. Often if a child is diagnosed with dyslexia, usually a parent will begin to acknowledge his or her own learning problem. Even though expert help may be sought by the parents to assist the student with learning disabilities or dyslexia, the child's difficulties may not vanish. Like physical illness, the symptoms of dyslexia run the continuum from mild to very severe. Expert help may assist the child, or the disability may be so serious that even with expert help the child may have a difficulty with learning to read. Thus, although dyslexia is not a physical illness, it may impact a family unit in a similar way.

Hartwig cites the 1969 work of Kubler-Ross that traces the "typical reaction of stress placed upon us when dealing with our emotions." (Hartwig, 1984,p.315). According to Hartwig (1984,p.315) when a child has been identified as having dyslexia, the parents experience the first emotional stage of denial. Parents may have difficulty with understanding the diagnosis of dyslexia, as well as believing their child may have dyslexia because the child in

trouble may appear to be "bright" or have gifts of athletic and/or artistic talent.

The parents may assume that either the child is really dumb and therefore should not have adequate, much less stellar or creative skills in any other area, or that the child is bright and therefore should not have trouble in any area. Both of these assumptions are false. All children, students with learning disablities, dyslexia, or not, have special talents as well as weaknesses.

According to Hartwig (1984), the second stage that is experienced by parents coping with the diagnosis of dyslexia is anger. Parents and therefore their children "place so much emphasis on school achievement and grades. They [the child's achievements] seem so important when comparing children that we feel jealous of our child's playmates who are not troubled by dyslexia." (Hartwig, 1984,p.315)

The third emotional stage experienced by parents is the bargaining stage (Hartwig, 1984,p.315). This stage may only be appropriate in relation to "a specific level of homework or special drills [that] is bargained for in order to gain privileges or favors." (Hartwig, 1984,p.315) The

identification of a learning disability may raise the fear among parents that their child will not be normal and will therefore be different from his or her peers.

The identification of this fear and the unknown impact on the child and the family may bring about the next emotional stage, depression (Hartwig 1984,p.315). Parents may see in their mind's eye the life of the child "spinning out of control." Parents may fear for the child's future. They may fear that the child may not be successful in the acquisition of higher education (college), or fear that the child may not hold a job and earn a living on their own independent of parental care. (Hartwig 1984,p.315).

The fifth emotional stage is acceptance. This emotional stage may occur on a continuum that may last days, weeks, months or years. It is at this emotional stage that parents may attempt to learn about their child's disability and begin to search for help. (Hartwig 1984,p.315)

The last emotional stage is hope. By this stage, many parents' fears and apprehension have been relieved via observation of the child or through correct information to understand the disorder of dyslexia. It is in this stage

that parents begin to realize that their child can learn, with appropriate support and instructional intervention. (Hartwig 1984,p.315)

In a more recent work, Harwell (2001) offers a Feelings-Reactions/Response chart to illustrate the emotional reactions of parents when they first learn the child is having problems in school. The intensity and duration of the parent reactions vary. These emotional reactions may or may not be voiced by the parent. Harwell divides the parents' feelings into five categories of emotions from the work of Hartwig (1984) and Kubler-Ross (1969). The five categories include: (a) shock/denial; (b) anger/guilt/blaming; (c) resignation; (d) depression; and (e) acceptance. (Harwell, 2001).

Harwell's (2001) work highlights predictable parental feelings and reactions when parents first learn of their child's difficulty at school. Harwell's parental feelings and reactions categories can be compared with the grief stages/reactions in the work of Kubler-Ross (1969).

In the first emotional stage of shock/denial, Harwell states that the parents deny that there is a problem. The

parent may comment they do not see the perceived difficulty (i.e., difficulty with reading words) when the child is at home in their presence.

The second emotional stage described by Harwell is anger/guilt/blaming. The parents of the child with the identified difficulty have conflicting emotions, which include anger at the child, the parents own feelings of guilt, and the feeling of blame directed toward the child, teacher, or school.

Harwell's third emotional stage is titled resignation. Harwell states that parents begin to try to dismiss the difficulty by stating that this is not a "new" problem, but rather just something that is inherent in the make up of the child. By voicing this dismissal, the parents try to trivialize the problem. This might allow the parent to feel they may be able to create some distance between themselves and the child. This assumption of distance may allow the parent to believe that they were in no way responsible for the difficulty in the child.

The fourth emotional stage noted by Harwell is the stage of depression. In this stage, parents express a

concern about what other people may think of their child with the difficulty. People's thinking of concern to the parents at this stage is the thinking of the relatives, neighbors, and school personnel.

The fifth and final emotional stage cited by Harwell is the stage of acceptance. Once the parent or family has been able to achieve this level, the problem can begin to be resolved. Feldman (2000) supports the acknowledgement of these categories of parental reactions. He concluded from his work with many families that the parents of his clients were usually baffled (in denial/shock) by their child's difficulty in school. Parents summarized, quite incorrectly that their child was simply not trying hard enough.

Stress Within the Family Unit:

Additional Implications

Teachers and parents must learn to understand and interpret the unsophisticated language and behaviors used by children regarding school related stress. Osman (1982) states that the common assumption among parents is that the child's dyslexia may only affect the acquisition of academic skills, such as reading, math, or writing skills. Osman

(1982) states that learning differences can create a myriad of social challenges. Specifically, the social challenges and problems in the daily life of the children and their families can be far more pervasive and anxiety provoking than the child's problems with reading and math (Osman, 1982).

Not every child or family's school experience is a positive one. This negative experience or trauma that assaults the family is "stress." Regarding stress within the family unit associated with a child with dyslexia, Gallagher, Beckman, & Cross (1983) concluded that "a better understanding of the stresses faced by the child and the family system can only enhance the relationship between professionals and the parents, since families spend significant amounts of time in interaction with professionals." (in Waggoner & Wilgosh, 1990,p.97)

Rodis, Garrod, & Boscardin (2001) identified stress factors from the viewpoint of the child experiencing the difficulty. They collected thirteen autobiographical stories written by students at four different colleges. The challenges may be unique but similar in the global sense.

Each story captures a penetrating look into the individual writer’s life and their life journey. The autobiographies demonstrate that these personal experiences are "powerfully influenced by families." (Rodis etc.p.226)

Parent-Professional Relationships

There are often difficulties in parent-professional relationships when a child is diagnosed with dyslexia. Smith & Strick (1997) state that most young children birth to age 5 are generally optimistic when tackling new learning tasks. Parents, other family members, and teachers find delight in interacting with the child as a learner and share in the happiness the child shows despite repeated failures in accomplishing a newly learned skill such as climbing the steps (Smith & Strick, 1997).

Smith & Strick noted that parents, teachers and other family members needed to be alert when the enthusiasm for learning starts to decline. Although many different factors may be attributed to this decline in learner enthusiasm, it generally will begin to show up when a child with a learning disability (one of which is dyslexia) will take place after a child begins school.

The work of Waggoner & Wilgosh (1990) focuses upon these parent-professional relationships in order to provide a clearer picture of the experiences of the families with learning disabled children by looking at the families in a variety of arenas: at home, in the school setting, and within the community. In the Waggoner & Wilgosh's (1990) research, there was active parent involvement among the study's participants. Parents assumed different roles "such as teacher and advocate. All of the families indicated the need for instruction at home. All parents described their teaching roles as entailing commitment, ability, frustration, perseverance, and time" (Waggoner & Wilgosh, 1990). “But at times, even though parental commitment was high, frustration and negative emotions (especially over homework) erupted.” (Waggoner & Wilgosh, 1990,p.97).

Waggoner & Wilgosh (1990) found that families placed their child's teachers in to one of two groups. Teachers were described either as "helpful, supportive, and flexible" or as "uncooperative, inflexible, and uninformed about learning disabilities."(Waggoner & Wilgosh, 1990, p.97). Finally, Waggoner & Wilgosh (1990) noted that it was

important for parents to have external sources of support from other family members, friends, school staff, or parent- or professional organizations. Seven of the eight families in the Waggoner & Wilgosh (1990) indicated that they were aware children struggled with self esteem issues such as negative feelings, lack of self esteem or low self-confidence (Waggoner & Wilgosh, 1990, p.97).

Many people outside of the family system are oblivious to many of the struggles of families of children with dyslexia. Also siblings in these families must cope with the loss of time, energy, and attention from their parents. Furthermore, the child with the disability is under the scrutiny of their siblings, parents and professionals. Smith & Strick (1997) note that if appropriate help is not provided to the child, disinterest usually develops into outright avoidance. Children begin to develop strategies to spare themselves the embarrassment and frustration of trying to accomplish tasks that are difficult or even impossible for them (Smith & Strick, 1997).

The challenge of the parent and professional is to be able to work together. It is only in doing so that they each

will begin to make progress toward "their common goal: that of giving the children the best possible chance to actualize their potential." (Waggoner & Wilgosh, 1990,p.113)

Summary

An individual surviving in a former historical time period would have needed to acquire some skills different from those skills that are needed to survive in the twenty-first century. Individuals of very long ago needed to be skilled at hunting and fishing to provide food for nourishment and survival. In the twenty-first century, there is a need for some different kinds of survival skills. Literacy is a survival skill that is needed to an extent now more than ever before.

Dyslexia is a disruption to the acquisition of those literacy skills. Individuals who have difficulty acquiring the skills necessary to successfully read and comprehend auditory or written information, despite adequate intelligence, are compromised in their quest to be literate. Falik (1995) has also found that "systemic and observable patterns of adaptive and unadaptive family responses to the

stress of a child's learning disability" (Falik, 1995, p.337) can be identified. Without recognizing or recording these unique adaptive and unadaptive response patterns in families, the child's relationship to literacy can be seriously jeopardized.

In addition, a better documentation and better understanding of the strategies used by children with dyslexia and their families "can only enhance the relationship between the professionals and the parents." (Waggoner & Wilgosh, 1990, p.97) Therefore, it could be hypothesized that with an enhanced relationship between the professional and the parents, dyslexia will not remain a hidden, often misunderstood, secret shame.

Chapter 3

Methodology

This chapter describes the target population, research instruments used in the study, overall design of the study, and data collection procedures. It concludes with some specific observations about the advantages and disadvantages of the research instruments as utilized with this particular study's target population.

Target Population

The target group for this qualitative case study was taken from the Summer, 1997 database of the Frederick Reading Center, Inc. located in Frederick, Maryland. In selecting the eleven families to participate in this study, the following criteria were observed:

1. The Frederick Reading Center, Inc. had been contacted by the selected family.
2. Each family selected for the study had the child receive individual tutoring from the Frederick Reading Center, Inc.
3. The child receiving the tutoring assistance from the Frederick Reading Center, Inc. was currently in or had

just completed the elementary grades one through five.

4. The families all resided in Frederick County, Maryland at the time of their selection.

Additional families included in the database, as of Summer 1997, of the Frederick Reading Center, Inc. were eliminated from the target population for one or more of the following reasons:

1. The family contacted the Frederick Reading Center for advocacy assistance only.

2. The family did not reside in Frederick County, Maryland.

3. The person contacting the Frederick Reading Center, Inc. was an adult (age 18 or older) seeking tutoring assistance for him or herself.

The Multiple Case Study Design

The nature of the issues to be examined in this study necessitated the use of a multiple case study design. Yin (1989), for example states, "that a case study format is the preferred methodology when investigating contemporary phenomenon within a real-life context, particularly when the

researcher has little control over the events." (Yin, 1989, p.77) An important strategy used in this present study's multiple case study design was that of the in-depth interview.

Dollard (1935), as stated in Marshall & Rossman, (1995) notes, "one understands a culture through the history of one person's development or life within it." (Marshall & Rossman, 1995, p.88). Other researchers such as Taylor & Bogdon (1974) suggest that the in-depth interview will produce "people's own written or spoken words and observable behavior."(Taylor and Bogdon, 1974, p.4).

Thus, the use of an in-depth interview approach puts an emphasis on the unique story of the child and the parents who make accommodations for dyslexia in their daily lives. In this study the in-depth interview asked the parents to retell their child’s story with question probes as needed by the researcher.

The Research Instruments

The five specific research instruments used to gather data for this study were:(a) parents' interviews, (b) children's interviews,(c) parents' reflection journals,(d)

children's reflection journals, and (e) the site survey. The purpose of the parents' interviews was to gather a biographical snapshot of the child and to determine what approaches or life strategies had been helpful to the parents in dealing with the child with dyslexia. (See Appendix E). The purpose of the children's interviews was to find out what approaches or life strategies were being used by the children to accommodate for their difficulty with dyslexia at home and at school, and to illuminate any feelings that the children might have about their dyslexia. (See Appendix I).

The purpose of both the parents' and the children's reflection journals was to provide an additional avenue to gather the feelings and strategies used by the children and/or their parents in their daily struggle to accommodate for the child's dyslexia. Also, this avenue was to enable the children to tell about how dyslexia impacted them at school and at home. (See Appendix K for further information on the parent reflection journal questions and Appendix M for further information in the children's reflection journal questions.)

The site survey was created for and given at the request of the director of the Frederick Reading Center, Inc. The survey's major purpose was to gather quantitative data in the form of feedback from the parents concerning the helpfulness of the services offered at the Frederick Reading Center, Inc. A secondary purpose of the site survey was to gather information for the Frederick Reading Center, Inc., about needs and services that could be provided by the center to assist the children and/or parents. Much of the data generated by the site survey was tangential to the goals of the present study and is therefore not elaborated at length here. (A copy of this survey appears in Appendix G. Appendix H presents a simple frequency analysis of the survey data.)

Data Collection Procedures

To introduce the researcher to the parents and the children in the sample population, a letter of introduction, signed by both the Director of the Reading Center, Inc., and by the researcher was sent to each family in the study. This letter was sent on the letterhead of the Reading Center, Inc. to the families in the Summer of 1997. After

the letters of introduction were mailed, follow-up phone calls were made by the Reading Center, Inc. Director and this researcher to schedule a time for the initial interview. At the time of the initial interview, the researcher obtained informed consent forms signed by the parents. (See Appendix B, Appendix C and Appendix D for Informed Consent forms.)

Interviews

The initial interviews with the parents and the children took place during Fall, 1997. The follow-up interviews with the parent(s) and the children were conducted in Spring, 1998.

The interviews of the parent(s) were scheduled for a timeframe of one to one and one-half hours in length. The children's interviews took approximately one half hour.

The interviews of the parents and the children were audio taped and an informed consent form for the audio taping of the parent interview and each participating parent signed the child’s interview. Once the initial interview was conducted with the parent(s), follow-up interviews were scheduled. The follow-up interviews allowed for additional

personal reflection on the part of the parent(s) and also allowed the researcher to probe with additional questions to gather further data. Follow-up interviews of both the parents and the children were conducted approximately six months after the initial interview.

Written Survey

At the conclusion of the interview with the parents, a written survey distributed to the parents about services offered at the Reading Center, Inc (See Appendix G and Appendix H). Using a Likert scale from one to five (with "one" being not helpful and "five" being most helpful), parents were asked to determine how helpful each of the services offered by the Frederick Reading Center, Inc. had been to the parents and the child. Space was provided on the survey for the parents to identify services not listed on the survey.

At the conclusion of the initial interview, both the parents and the children were offered the choice of a small composition book or a blank audiotape tape to register or elaborate on additional life experiences in which there was an accommodation made for the dyslexia.

Before the blank audiotape was given to the parents or the child, the researcher ensured that the individual had a fully functioning recording device (tape recorder) in the home and that the individual knew how to use it so that data could be obtained in this manner.

Pilot Study

A final note about the data collection in this study concerns the pre-testing of the items on the Parents' Interview schedule. In a small pilot study conducted in early 1997, four adults known to the researcher were asked to answer question #13 of the Parent Interview (See Appendix E for the Parents' Interview Form. Question #13 reads: "Tell me (Child's Name) story.") This pilot test was conducted to determine if this particular question would gather useable data about raising a child with dyslexia and the life strategies used by the parents as they raised their child. It was subsequently determined that this question was indeed a viable one for gathering information pertinent to this study. One parent (in the pilot study) in particular told the story of raising a child (a daughter) with dyslexia. At the end of her story, and without prompting by

the researcher, she started to analyze what she had told the researcher. Her stated analysis of the emotional stages that she went through while raising her child with dyslexia matched almost exactly the order of the Kubler-Ross (1969) categories of denial, anger, depression, bargaining, acceptance and hope. In her analysis of what she had said, she specifically mentioned the emotions of denial, anger, bargaining, and acceptance.

The other three parents in the pilot study expressed anger either at the child, classroom teacher, or the school system. Life strategies used by the parents (e.g. weekly calls to the classroom teacher during the school year, writing "check-off lists" with the child for doing homework, working with the child to develop better athletic skills, and bargaining over homework) were also mentioned to the researcher.

The Research Instruments and the Study Population: Some Limitations

The three general research methodologies chosen for this study (interview, self-reflection journals, and survey) do have their limitations. Surveys, for instance, can be

general in nature that they may appear superficial. The self-administered survey may also be subject to the respondent's attitude at the time the questionnaire is being completed.

Likewise, the personal interview has both advantages as well as disadvantages. On the positive side, the personal nature of the interview allows for immediate feedback, and for the opportunity to follow up with questions to obtain additional data. Yet interviews, as a research method, also have the limitations of subjectiveness and bias on the part of the interviewer.

Interviewing elementary aged children in particular has its advantages as well as disadvantages. On the positive side, Fivush et al. (1991) found that children "reported more accurate autobiographical information when conversing with a stranger" (in Steward, 1996, p.24). On the other hand, Dent (1977) and Peters (1987) note that "when children feel intimidated by any stress they may perceive in an interviewer's manner or tone of voice, they may "shut down". (in Steward, 1996, p.25)

The use of the journal to record the parents' and the

child's observations can also be a subjective, but revealing, tool. Overall however, in the context of the present study, the use of multiple methodologies-despite their individual limitations-did, when taken together, provide useful insights into the study's major research questions and thus proved to be effective research tools.

Chapter 4

Results, Analysis and Discussion

This chapter provides a breakdown of the children as well as the parents who participated in the study. This chapter also has the individual family case stories and documents the research findings. This chapter also includes an Analysis Section which provides a content analysis of the study and an examination of both the comments of the parents and the insights of the children. The Discussion Section which relates the study findings to previously cited literature places the perspectives of the parents and the children within a larger framework.

Introduction

The children who participated in this study were all elementary aged students. A brief description of the children in the study (N=11) is shown in the following table.

Table 4-1

Summary Table of Children Participating in the study

School Grade	Gender	
	Male	Female
Kindergarten	0	0
First Grade	1	0
Second Grade	1	1
Third Grade	1	1
Fourth Grade	4	0
Fifth Grade	1	1

N=11 elementary aged children

The gender distribution in this study was eight males and three females. The elementary grade school distribution was the following: one child in first grade, two children in second grade, two children in third grade, four children in fourth grade, and two children in fifth grade.

The ethnic composition of the children participating in this study is shown in the following table.

Table 4-2

Summary Table of the Ethnic Composition of the Children Participating in the Study

Ethnic Composition		
African-American	Hispanic	White
2	2	7

N=11 elementary-aged children

A breakdown of the composition of the parent interviews and the children's interviews was as follows: one(1) mother and father, both present at the parent interview of their one (1) dyslexic child attending the Frederick Reading Center, Inc., were interviewed together; one (1) father of one (1) dyslexic child was interviewed; five (5) mothers, each mother with a dyslexic child and one (1) grandmother with one (1) granddaughter with dyslexia were interviewed; one (1) mother with two (2) children with dyslexia was interviewed. Neither parent of one (1) of the children

interviewed was unable to schedule a parent interview with the researcher; however, the child was interviewed in this case (See Appendix C for the Parent Interview protocol).

Table 4-3

Breakdown of Parent Interviews

Person Interviewed	Number of Adults Interviewed
Father Only	1
Mother Only	6
Grandmother Only	1
Father and Mother Interviewed Together	1
Parent or Grandparent not interviewed	1

N=9 interviews conducted

Individual Family Case Stories

The information from the Parents' Interviews provided a very rich data source through which the individual Family Case Stories could be constructed. These individual family case stories proved to be the centerpiece of the study

findings. The individual family case stories are reported in the following examples.

Jim's Story:

Ten-year-old Jim attends a local elementary school to which he has been assigned because of that school's proximity to the suburban development in which he and his parents live. Jim lives with his mother and father. He has an 8-year-old sister who lives with him and his parents in their home and an older sister and an older brother who do not currently live in the home.

The older brother also had difficulty learning to read, but the older sister did not have any difficulty with any academic subjects in school. The younger sister has not yet had any difficulty learning to read.

Jim goes to the Frederick Reading Center, Inc. once a week for tutoring. During the parents' interview, where both parents were present, the mother did most of the talking. There were no difficulties noted in Jim by his parents until he was three or four years of age and his mother was starting to work with him on learning the alphabet. Despite the many strategies employed by the

mother, she was unable to successfully get Jim to learn to recognize all twenty six letters of the alphabet by the time he was ready to start kindergarten. Jim's difficulty with letter naming persisted throughout his kindergarten year. His kindergarten teacher suggested that Jim have educational testing done at the school to see if he had a learning disability. Jim's parents requested that the school provide that testing at the end of the first term of his first grade year. By the end of December, and as a result of this testing, Jim had been identified as having a learning disability in the areas of reading, math, and written language.

Jim received services from the special education teacher in a pullout program. A pullout program involves removing children from their regular educational classroom and instructing them in a separate location. Jim's academic skills improved slightly with the intense help he received. His parents were frustrated with his progress, but were willing to support the system. Jim's parents noted that grades 2 and 3 were difficult years for him. His reading, writing and math skills lagged behind his peers. Further,

his parents noted that the communication between them and Jim's teacher was not consistent or clear, his daily assignments went uncompleted, and his grades fluctuated. The parents said both the second grade and the third grade teachers were "not helpful" to them in either suggesting activities to do at home or in suggesting places to gather information or help. It was during this time that the parents formed a Cub Scout group in which their son Jim was a member.

In third grade, Jim's parents signed him up to play football. Jim's father was especially interested in developing his son's athletic and communication skills. The parents proudly showed Jim's trophy collection to the researcher and noted that Jim had been named a team captain (by popular vote of the football team) because of his ability to "get along with his teammates."

Jim's present fourth grade teacher was called "helpful" by both parents. They felt this year's teacher "understood" Jim and, although he was still being pulled out for special services to assist his reading, writing, and math skills, both parents felt that the teacher made daily accommodations

for him (e.g., extra time to write down assignments, use of manipulatives to complete math computations). At the time of the interview, Jim's parents had just received a letter from the school saying that he was unable to write the answers to basic addition, subtraction, and multiplication and division facts. The father stated in an angry manner (as he showed the letter to the researcher) that they (the school) had sent the letter because "our son was ruining their curve." (Jim's school had been chosen as a "Blue Ribbon" school two years earlier. A Blue Ribbon school is a school that has been identified as a high performing school by the Maryland Department of Education.)

Penny's Story:

Eight-year-old Penny lives with her mom and dad and receives tutoring at the Frederick Reading Center, Inc. one day per week. She has two older siblings, a brother age 19 and a sister age 17, who also live in the home. Neither parent was able to schedule an interview, but the child herself was interviewed. Additional details of Penny's story pertinent to the present research emerged through Penny's interview, and her self-reflection journal, and the self-

reflection journal kept by Penny's parents.

Mike's Story:

Ten-year-old Mike lives at home with his mom, dad, and a younger sister. Mike's mother described him as a "great baby." However, during his preschool years Mike was always struggling to stay at "grade level" and experienced difficulty with activities the other children were asked to do at the preschool. His mother noted that Mike sometimes had trouble staying on task. He repeated first grade. Mike's mother felt that with the tutoring that he received in 1997, he was able to "maintain" and keep up with his peers. She noted that his progress in 1997 was "good". His progress this year (1998) was reflected at the time of his first report card as A's and B's with one C in Language Arts (Reading and Writing).

Mike's mother indicated that there were not many children who lived in their neighborhood. However, Mike was now attending Boy Scout meetings and enjoyed playing soccer in the Youth League.

Billy's Story:

Billy, (age 10) is an only child who lives with his mother and father. His difficulty began in third grade. His father indicated that at that time Billy had trouble "settling down" and doing "reading and homework". His father also said that Billy had trouble organizing his work and studying.

During first and second grade, Billy attended a Christian school which the father described as "fantastic". Billy was transferred to a public elementary school after his father's company was downsized and his father's job transferred out of the state. The father enrolled his son in the elementary school that the father had attended as a child.

Billy's father indicated that in fourth grade Billy had difficulty with problem solving (i.e., reading a given math word problem and following the steps to solve the problem correctly). The father said that in fourth grade Billy had been moved to the "slow group"; however, at the end of that year he had been moved to the "higher" group. In fifth grade, Billy's difficulty was in the area of written

communication. The father mentioned that Billy had difficulty organizing his thoughts and writing them down like "they" (the teachers) wanted them. The father indicated that he felt that Billy really didn't have any difficulty, and that he just brought him to The Frederick Reading Center, Inc. for help in study skills and writing.

Billy's outside activities include playing the drums in the band and taking drum lessons. Billy's father said that he did not want his son to be "average" and that he (the father) tries to connect Billy's "learning process" with sports. (The father did not elaborate further on these comments, although asked to by the researcher.)

Nathan's Story:

Eight-year-old Nathan is one of three children currently living at home with his mother and father. He has one older brother (age 11) and one younger brother (age 4).

The parents indicated that Nathan had attended a small private school since first grade. According to his mother, Nathan was receiving speech therapy in October of 1996 as a first grader. He also had a reading specialist working with him at that time. According to the mother, the reading

specialist did not want to "push" Nathan to read words because he could not phonetically produce sounds due to the difficulty with his speech acquisition. However, the mother indicated that the speech pathologist did have Nathan read during the speech sessions.

Nathan's mother stated that one of the things that had contributed to her child's difficulty was massive ear infection as a toddler and preschooler. She indicated that Nathan had been on year-round medication and that she and her husband were unsuccessful in getting their pediatrician at the time to put tubes in Nathan's ears or to remove his tonsils. The parents subsequently took Nathan to a new pediatrician and requested that this physician schedule the removal of Nathan's adenoids. After Nathan's adenoids had been removed, the new pediatrician described this child's difficulty as part speech problem and part allergies.

Nathan's mother indicated that Nathan's kindergarten teacher noticed that he was a "different child". He tended to pick things up quickly, but he had to "overwork" when it came to learning alphabet letters and their corresponding sounds. Nathan's mother also stated that in first grade he

could not "phonetically spell."

Nathan was described by his mother as being "good natured", fun loving, and really smart. She also said that it takes him a long time to read something. She is surprised that he reads aloud as poorly as he does and at the same time, does well with his reading comprehension. Nathan's mother said that he had "an easier road to tow" (quote) because he had learned a lot from his brothers.

Amy's Story:

Seven year old Amy lives with her mom and step dad, three brothers and two sisters. Her grandmother, who lives two houses away, brings several of the grandchildren for tutoring and oversees the children's schooling. The mother is a private duty nurse's aide and is on call and maintains an unusual work schedule. The two younger brothers (grade 1 and Kindergarten) come for tutoring with Amy, but the sisters (who are older) do not come.

The grandmother indicated that she noticed Amy's difficulty in the first month of first grade. Specifically, she noticed that her granddaughter was not doing anything.

According to the grandmother, Amy was not able to recognize alphabet letters. The grandmother indicated that she had talked with the mother and wanted to get help for her granddaughter but was not able to get help from the school that her granddaughter attended. The grandmother said that she was still interested in getting help, but did not know how to get the school to respond to her requests. She said, "As long as you don't make trouble, they tend to ignore you." The grandmother indicated that the teachers and school administrators would not speak with her about Amy's problems because she was not the child's parent. She said that the school would only speak with her if the mother was present at any meeting. She credits the Frederick Reading Center's director with helping her (the grandmother) pass along information to the child's mother about how to access services from the school.

Jamie's Story:

Jamie (age 10) lives with his mom and half-sister. The father has not been present in the home for some time. Jamie is currently functioning a year below his grade level.

Jamie's mom has been very unhappy with her child's

schooling since first grade. She stated that she was called two weeks before the end of Jamie's first grade year and was told by his teacher that her son should be held back in first grade. She refused to agree with this. She feels that the school has been withholding information from her since her son's first grade experience.

Jamie's mom said that the school knew he was reading on a first grade level at the end of first grade. However, the mother indicated that when her son was given reading assignments, she saw no problems. She indicated that he did not have any writing assignments in first grade. She stated that her son was a "graphic" dyslexic because he had difficulty in reading and spelling. His mother felt that if the school had tested Jamie more than once, he would be on-grade at the fourth grade level at this time.

Jamie's mother said that she was never told what her son was doing in school and was never given things to do at home with him. She said that she was not told about his difficulty in spelling until the end of third grade. She indicated that until the November parent conference of this

year (fourth grade); she was not told about his problems in math.

Jamie's mother stated that her son's most successful year was in kindergarten. Although he was one of 23 children in the kindergarten class, she indicated that the teacher managed to "make him work."

His mother remembers first grade as a year of behavior problems for Jamie. She said that at the parent conferences, only behavior problems were discussed, and that she was never told about Jamie's learning problems. She indicated that the teacher said Jamie refused to do assignments. The school wanted to hold him back in first grade for behavior problems.

Since Jamie was entering second grade reading at the last half of the first grade level, the mother requested testing by the school. At this time she also requested counseling. The mother then terminated the testing at the school level and had Jamie tested at Brooklane Hospital (a mental health care facility) for ADD/ADHD (Attention Deficit Disorder/ Attention Deficit Hyperactive Disorder) and for educational disabilities. Her son was prescribed medication

as a result of the testing for ADD/ADHD.

The mother indicated that she requested assistance from the school during Jamie's second grade year, but none of her requests were acknowledged. She said that the second grade teacher's class was unstructured and that the teacher never tried to help her son, although the mother made numerous calls to this teacher.

By the time that Jamie was in the third grade, the mother indicated that she still was requesting help and called the Board of Education to voice a formal complaint. She said that the assistance offered by the school could not make up for three lost years. The mother indicated that she was angry, furious, and “fit-to-be-tied.” She called Jamie's third grade year "a horror story." She also related that in second and third grade Jamie lost his recess privileges and stood against the wall 95% of the school year. She felt that the school took away any chance for Jamie to improve in his social skills. Jamie's mom indicated that he only has one friend and that he is picked on by the other children. She says that it is now school policy that her son does not lose his recess. However, she indicated

that a 504 plan is now in effect for her son. A 504 plan refers to Section 504 which is part of the Rehabilitation Act of 1973 that prohibits discrimination based upon disability. Section 504 is an anti-discrimination, civil rights statue that requires the needs of students with disabilities to be met as adequately as the needs of the non-disabled are met.

Jamie's 504 plan allows him to do his homework on a computer because of his poor "penmanship" (spelling and writing skills) and to do his written work at school on an AlphaSmart computer. An AlphSmart computer is a simple, lightweight, rugged portable and virtually indestructible kid proof low cost computer that allows children to enter and edit text. Also, Jamie's mother said that nothing comes home that needs instructions. (This means that any school work or work that was to be done at home was to be able to be completed independently by Jamie with 90-100% accuracy.)

The mother said that they live in an isolated area and that she has to drive to the nearest neighbor. She said that Jamie is now participating in a Boy Scout group led by one of the parents that she has met at the Frederick

Reading Center, Inc. In summary, Jamie's mom feels that the school system is "playing games" with her and that none of her requests have been met.

Steve's Story:

Seven-year-old Steve is the older of two children who live at home with Mom and Dad. Steve's younger brother (6 years old) was diagnosed with autism at the age of two.

The mother indicated that Steve spent his pre-school years attending a local Montessori school. He had attended the Montessori school in the afternoon because she worked. She stated that the school covered the "academic stuff" in the morning, and the family was basically using the afternoon time in the school as childcare. She stated that her son was missing the academic instruction by having him attend school only in the afternoon.

Steve was enrolled in his local pubic elementary school in kindergarten. He made many friends, but he had some social difficulties in the after-school program overseen by the local YMCA.

When Steve entered first grade, he was put into a "very fast moving" group and he had a hard time adjusting to the

pace of the group and to the amount of reading required.

Steve's mother said that he had been expected to read a 60 page first grade book in one night. She also said that Steve would spend an hour and a half every school night doing his homework for first grade.

Steve's first grade teacher told the mother that she suspected that Steve might have a learning disability (dyslexia), and the parents agreed to testing. (Steve's mom also had him independently tested.)

Steve has been going to the Frederick Reading Center, Inc. for tutoring once a week. However, at the time of the interview, Steve's mother said that she had discontinued the tutoring because Steve had continued to make progress in school and had caught up with his peers. She felt that he had adjusted to the demands of school and was progressing well. She also indicated that she had recently become a parent volunteer in her son's classroom, and that Steve looked forward to the days that she came to volunteer. In her capacity as a parent volunteer, Steve's mom works with small groups of children, either listening to them read or helping them with their spelling or writing (whichever the

teacher requests her to do on that day.) She stated, "whenever I'm not there, something happens." Steve's mom said he now likes to play basketball and to attend the after-school YMCA program held at his school.

Kimm's Story:

Kimm (age 10) lives at home with Mom and Dad and one of her brothers (age 12). Her two older brothers do not currently live at home.

The mother indicated that Kimm's difficulty began during first grade, but educational testing was not conducted by the school until the end of first grade. The mother noticed that as her daughter was reading the books used in the first grade. Kimm memorized the books, but was unable to read the words when they were presented in isolation. The mother also reported that Kimm was unable to complete any written work because the way that Kimm formed her alphabet letters made her unable to keep up and complete her written work. She could however, use a pencil and doodle on paper. Kimm's mother said that Kimm did not qualify for the Alphaphonics program (a program offered in the Frederick County, Maryland School system to children who are

identified as having dyslexia) because she was always too old. (In other words, if her daughter was in second grade, the only Alphaphonics group available was in first grade.)

Kimm's mom said she kept pushing and kept thinking that the next year, things would work out. However, her daughter was in fourth grade and was still printing, but not legibly. Everything in the fourth grade classroom, however, was completed in cursive writing, not printing.

The mother indicated that Kimm's progress this year (fifth grade) has been "fair." She stated that the teacher seemed to understand her daughter's special needs and was willing to help implement her special accommodations in the classroom this year. However, the mother is not content that Kimm is still unable to write in cursive, and objects to the handwriting papers sent home for Kimm to complete on her own. She feels that the school should teach her daughter to write in cursive. The mom states that every year for her daughter has been different.

Tim's Story:

Tim (age 9 and 1/2) lives at home with his Mom and Dad, a 17-year-old sister and two brothers, (ages 3 and 6 and

1/2). An older sister who is 21 is living away from the family in her own apartment.

The mother reported that Tim's difficulties began at the end of first grade. The school recommended that he enter the dyslexia program that was being offered at the school in Grade 2. The mother reported that there was nothing on the report card and nothing at the parent conferences to indicate that Tim was behind in the area of reading. She said that Tim's behavior was a problem, that he was bored, and that the teacher did not know how to teach him.

Although Tim received Alphaphonics instruction at his school in Grade 2, the mother reported that she received no cooperation from the school. At that time, she informed the school that Tim was working with a tutor. The mother said that Tim's second grade teacher had been given six "bad" kids (Tim was one of them) and that she put them in the back of the room. The mother further stated that the six "bad" kids could earn rewards to get to go up front and that Tim wanted to earn the rewards to get up front. The mother said that she felt Tim learned more in one hour of tutoring at the Frederick Reading Center, Inc. than in school.

The mother indicated that third grade was a little better for Tim. She had wanted to meet his teachers before the school year began. However, the school was not able to provide the mother or Tim with an opportunity to meet with the third grade teachers. Mom reported that two of Tim's three teachers during that year worked with her, but she had to keep tabs on him and "was practically at the school every day."

In fourth grade, Mom was having difficulty establishing communication with Tim's teachers. She stated that the Alphaphonics program (in which Tim had continuously participated since grade 2) was a wonderful program, but she wanted Tim to have the Alphaphonics instruction as soon as he came to school, instead of when it was offered in 4th grade, which was from 2:30 to 3:15 p.m.

Mom requested and receives daily reports from Tim's Alphaphonics teacher and a daily parent letter as to whether Tim had a `Good Day' or a `Bad day'. Mom stated that Tim has trouble keeping on task because he is bored with school. She stated that Tim has a high I.Q. but is not eligible for any special services other than Alphaphonics.

The mother stated that her son has been diagnosed with ADHD (Attention Deficit Hyperactive Disorder), but she does not believe in medication. She stated that a chiropractor has helped Tim with his ADHD through a series of treatments. She said she would use herbs first (before medication) to address the ADHD.

Jeff's Story:

Jeff, Tim's younger brother, is 6 and 1/2 years old and in the first grade. The mother reported that when Jeff was a toddler, he fell down the basement stairs and fractured his skull. Although asked by the researcher in the interview, she did not elaborate on any treatment that Jeff received as a result of the fall.

Jeff's mom stated that she had wanted to hold him back so that he could repeat his kindergarten year. She also hired a tutor during his kindergarten year because he could not recognize and remember the letters of the alphabet. She went on to state that she felt that Jeff's short-term memory had been affected because of the accident. (The mother stated that she had received the information about short-term memory loss as the result of a fractured

skull from her sister who was taking a psychology course at a local community college.)

Jeff's mother said that his first grade year could have been better. She said that Jeff does not qualify for any Special Education services provided by the school, but that he received services with the Reading Specialist who reinforces what happens in the classroom. The mother stated that school seems to be the least thing that Jeff is bothered about.

Additional Data Sources:

The Parents' Self Reflection Journals and the Children's Self Reflection Journals

In addition to detailing their family stories in the Parents' Interviews, the parents utilized the Parents' Self Reflection Journals to describe many of the concerns that they had about raising a child with dyslexia. (See Appendix J for the raw data from the Parents' Self Reflection Journals.)

The Children's Self Reflection journals (See Appendix L) provided some additional information about the daily

challenges they faced living with dyslexia. A content analysis of all of the study instruments (Parents' Interviews and Parents' Self-Reflection Journals, Children's Interviews and Children's Reflection Journals) revealed some common themes.

The Parents Speak:

Challenges at School and at Home

In the present study, the parents recounted their experiences and feelings about raising a child with the identified disorder of dyslexia. The two major instruments used to gather this data from the parents were the Parent Interviews and the Parent Reflection Journals. The interview proved to be the more successful of these two formats in gathering information from the parents. (See Appendix C for the raw data from the Parent's Interviews and Appendix J for the raw data from the Parent's Self-Reflection Journals,) upon which the content analysis is based.

During the Parent Interviews, and to a lesser extent in the Parent Reflection Journal, the Parents spoke about their frustrations in coping daily with children with the

identified disorder of dyslexia. Common ground was discovered among all the parents as they spoke about their and their children's daily life experience.

Theme 1: School Difficulties

School difficulties was the most frequently mentioned issue by the parents as they related their family stories to the researcher in the Parents' Interview. Another research instrument, the parent self-report reflection journals also provided strong confirmatory evidence of this theme. The ten parents interviewed repeatedly reported the struggles of their children to grasp the academic content being taught in the school and also their child's difficulties with social issues such as following school rules and making friends. The family members interviewed recounted many examples of daily and yearly educational struggles of the child. Although every story related to the researcher by the family member was equally poignant, Jim, Jamie, and Kimm's mothers' in particular gave a brief year-by-year summary of their struggle to acquire both academic skills and social (peer-group) acceptance.

This longitudinal overview helped to highlight another common theme in the study findings that: the type of school difficulty experienced varied with the child's year in school. Jim's mom, for example, stated that even with intense help, Jim's academic skills improved only slightly when he was in first grade, and in second and third grade Jim was still not catching up with his academic skills. Kimm's mother also expressed a similar experience for her daughter. Although Kimm had struggled academically since first grade, her mother kept pushing and kept thinking that in the next school year, things would work out.

Likewise, the timeframe that the parents identified as being the beginning of the school difficulties for their child was very similar, according to most of the parents. In six of the ten families, the parents specifically said that their child's difficulty began in first grade. This finding is not surprising, since the importance of recognizing alphabet letters and associating their corresponding sounds in Grade 1 coincides with the introduction of an increasing emphasis on the printed and written word. It would make sense then that children who are identified with dyslexia

would begin to experience difficulty at this particular age.

However, alphabet recognition, sound-symbol association and beginning word recognition can also be a part of Pre-Kindergarten and Kindergarten instruction. One of the parents interviewed stated that their child began having difficulty in the child's pre-school years, stating that they noticed between the ages of 3 and 4 that their child had difficulty learning the alphabet.

Two of the families interviewed stated that their child's difficulty with acquiring alphabet letter recognition and corresponding sounds began during the child's Kindergarten year. One of these two parents indicated, the kindergarten teacher noticed that he [her son] was a different child. He tended to pick things up quickly, but he had to overwork when it came to learning alphabet letters and their corresponding sounds.

Only one parent interviewed felt that their child did not have any academic difficulties until grade 3.

Theme 2: Challenges Experienced by the Parents Related to their Child's Difficulties in School

A common reaction reported by the parents of the

children with dyslexia was the parent's own difficulty and frustration with the school. Jim's mom noted that during his second and third grade school year clear and consistent communication was difficult for her to establish with his teachers. Tim's mother indicated that she "was practically at the school every day" because she felt she had to "keep tabs" on her son. Jamie's mother also indicated that she was "angry, furious and fit-to be-tied" because she felt that assistance from the school could not make up for her son's "three lost years." She felt that the school had been withholding information from her since Jamie had been in first grade. (At the time of this study Jamie was in Fourth Grade.) Jamie's mom also said that she was never told what her son was doing in school and was never given things to do at home with him.

Other but less commonly, expressed emotions by the parents could be labeled denial and bargaining/hope. Regarding denial, one father stated during the parent interview that "he felt [his] child really didn't have any difficulty" and that he "just brought him (to the Frederick Reading Center, Inc.) for help in study skills and writing."

Tim's mother said that her son's "behavior was a problem because he was bored and that teacher did not know how to teach him."

Regarding the emotion of bargaining/hope, Kimm's mother expressed an example of these emotions when she stated that "she [the mother] kept pushing and kept thinking that the next year, things would work out." All of these various examples of denial, frustration, and bargaining/hope were stated by the parents in relation to the child's (and therefore the families') struggle in the child's school career. Moreover, the present study found that these struggles both academically and socially, continually began anew. Each year, each month, each week, and each day, many of the parents and children thought and silently hoped that things would be different. But most of the time, they were not.

Theme 3: Teacher Helpfulness

Kimm's mother's response is typical of this cyclic pattern. For example, Kimm's mother told the researcher in an exasperated tone of voice, "Unfortunately <u>every</u> year is different! We have had a great teacher who is willing to do

and try anything/everything for her. We had [another] teacher who let her slide whenever anything was too tough for her, which really impaired her progress that year." This cyclic pattern (always "starting over" at the start of each new school year) can be linked to another major theme that emerged from the family stories: the parents' perception of how helpful or not helpful various teachers had been to their child. Teacher helpfulness was identified by the parents as a broad, overriding category which showed a breakout into three recurrent sub-themes: (a) Parental perception of adequate communication between the teacher and parent; (b) Parental perception of teacher accommodations for the child; and, (c) Parental perception of direct additional assistance given to child and to the parents. That is, the parents felt that teachers were helpful if 1) the communication between the parent and the teacher was clear, or if 2) the teacher was able to make accommodations to assist the child with his/her learning, or if 3) the teacher was able to assist the parent with clear and understandable ways in which the parents could help their child with learning. Of these three sub-themes, the

dimension of communication appeared to be of the greatest importance to the parents in assessing teacher helpfulness, with the other two sub-themes closely linked to it.

Some specific examples of parental perceptions of the theme of teacher helpfulness emerged from the parent interviews concerning Jim, Kimm, and Jamie. For example, Jim's fourth grade teacher was called helpful by both of Jim's parents. They felt that the teacher understood Jim and that the teacher made daily accommodations for Jim by allowing him extra time to write down assignments and allowing him to use manipulatives to do math computations. Kimm's mother stated that Kimm's teacher seemed to understand her daughter's special needs and was willing to help implement her child's special accommodations. Jamie's mother stated that her son's most successful year was his kindergarten year because the teacher managed to make him work. After many meetings with the school and his teachers Jamie's mother said that in Grade 4 he (Jamie) could now do his written work at school on an Alphasmart computer because of his difficulty with handwriting, spelling and writing skills. This accommodation was written onto Jamie's school

504 plan. The content analysis of the study findings similarly uncovered a teacher non-helpfulness dimension. The teacher non-helpfulness theme evidenced itself in categories of parental responses, which focused upon resources that were not perceived to be available. Like teacher helpfulness, the theme of teacher non-helpfulness can also be categorized into three sub-themes: (a) Parental perception of a lack of communication and/or cooperation between the school and the home; (b) Parental perception of a lack of specific information about the child's learning difficulty from the child's teacher; and (c) Parental perception of a lack of resources or assistance to the child or parent from the school and/or teacher.

As in the case of teacher helpfulness within the theme of teacher non-helpfulness, the element of difficulty in communication between the parent, child, teacher and school was identified as the parents' main concern. For example, Jim's parents felt that the communication between them and Jim's teachers in Grades 2 and 3 "was not consistent or clear, and daily assignments went uncompleted while his grades fluctuated." Amy's grandmother stated, "as long as you don't make trouble, they [the school] tend to ignore

you." Jamie's mother said that she was never told what her son was doing in school and was never given things to do at home. (She also said that she repeatedly requested assistance from the school, but that none of her requests were acknowledged.) Tim's mother reported "there was nothing on the report card and nothing at the parent conferences to indicate that her son Tim was behind in the area of reading." Again, as in the teacher helpfulness dimension, the subtheme of communication is dominant and serves as a link to the other two subthemes here (perceptions of lack of information and perceptions of lack of assistance) in identifying teacher non-helpfulness.

The Children Speak:

Challenges at School and at Home

The two major instruments in the present study from which the children with dyslexia articulated their experiences and feelings about their dyslexia were the Children's Interviews and the Children's Self-Reflection Journals. The interview proved to be the more successful of these two formats in eliciting this kind of information from the children. (This was probably the case because the

Children's Interviews were personal, face-to-face encounters (with opportunities for probes by the researcher), and also because the Children's Self-Reflection Journals-even in audiotape format- may have been difficult for the children to use, given the nature of their dyslexia. (See Appendix H for the raw data from the Children's Interviews and Appendix L for the raw data from the Children's Self-Reflection Journals, upon which the following content analysis is based.)

In their interviews, and to a lesser extent in their journals, the children often spoke about their daily life experiences with dyslexia. Attending school and the tasks within the school day (academic tasks like reading and writing, and also social tasks) were all-important parts of the individual children's daily life experiences. As all of the children in the present study spoke in this way about their daily life experiences with dyslexia, three common themes emerged.

Theme 1: Emotional Consequences of Dyslexia to the Child

The most frequently expressed theme that emerged from the children interviewed was the theme of nervousness and

anxiety. The next two themes expressed in frequency by the children were the themes of anger and of faking it (pretending to know when the child felt they really did not know).

When the children were asked during their interview "How does having difficulty when you read affect you?" the children responded by telling about their feelings when they were reading and accommodating for their dyslexia at the same time. Tim and Nathan both admitted that they were "nervous" when they were reading. Kimm said that when reading she often "lost her place." (This could be a child's way of saying that she was nervous when she read.) Amy admitted to feeling "woozy like I just feel like I'm frozen." Three of the children (Jeff, Billy and Nathan) admitted to feeling "mad." Nathan's said that when he reads his "Dad tells me to leave the anger out." Penny's response to the question of having difficulty when reading, spoke of "faking it" when she read. Penny said, "I read it. I hope I know it. I follow along."

Theme 2: Emotional Consequences of the Child's Dyslexia to the Family

From the child's perspective, the theme of the consequences to their families of their dyslexia was present, but difficult to bring to the surface.

During the children's interviews there also appeared to this interviewer either an inability or reluctance on the part of the children to articulate the emotional toll that dyslexia was having on them as well as their families. Nathan said that his difficulty with reading, "affects Dad really bad." "He wants me to be smarter." Amy reported that her parents get "frustrated" and say to Amy "Man, somebody better help me."

Theme 3: School Difficulties for the Children

The children themselves freely spoke however of difficulties in academic school subjects such as Spelling, Reading and Math, reinforcing the school difficulties theme that the parents had identified in their interviews. While the children often identified difficulties in a particular subject, they were also likely to state that their dyslexia

spilled over to affect their mastery of multiple subject areas.

Jim for example, identified Spelling as a difficult subject for him because "it was hard to know the letters." Nathan said that Reading was a difficult subject for him because "it's hard to understand the words because of all the different shapes and sounds." Amy was a child whose difficulty with reading followed her through three academic subjects (Reading, Spelling and Math). She simply stated that she had "to work hard" in the three subjects she mentioned. Steve saw his difficulty in reading affecting his Math. He felt he struggled through Math "because sometimes we have to do complicated things like read the story [math word problem] and you have to do something with it [such as comprehending what the problem is asking and then writing a response]. Jeff, the First grade member of this research population, said that he had difficulty with reading what he described as the First grade "hard books" and "counting."

Fifth grader Kimm felt her dyslexia was interfering with her ability to remember the steps needed to complete a division problem. Yet, on a positive note, Kimm mentioned

that her difficulty with reading was assisted in her Language Arts (Reading, Spelling, and Writing) classes because she was able to "work in smaller groups and work with the Special Education teacher four times a week."

Life Strategies for Dealing with Dyslexia: Two Viewpoints

A final overall thematic area that can be gleaned from the study findings has to do with what can be termed life strategies. Parenting children creates a continuous array of competing realities. At times there are no easy answers, no predictable formulas to follow, and no one right answer. The compensatory strategies (or lack of compensatory strategies) that children and families develop in order to learn how to live with dyslexia is one of those realities. In the present study, both the parents and the children were asked about their strategies for living with dyslexia. Many of these life strategies emerged in the context of the personal interviews.

Life Strategies from the Parents

Parents (and other family members) develop many different ways of living with children with dyslexia and who

are having difficulty because of this. The particular strategies that the children and families develop are also as varied as the individual children and families themselves.

In the present study, the strategies employed by the parents to accommodate a child with dyslexia appeared to be framed around three life strategy pathways. These three pathways were (1) encouraging their child's natural abilities and talents, (2) finding social outlets for their child and (3) advocating for their children at school.

The first life strategy pathway was the parent’s perception and encouragement of the dyslexic child's natural talent in a particular area such as athletics or music. Jim's father, for example, signed him up for football in third grade to nurture his son's athletic ability. Billy's dad encouraged his son to take up a musical instrument (drum) and paid for drum lessons for Billy. Mike's mother signed Mike up to play soccer in the Youth League while Steve's mother signed him up for basketball.

In a second life strategy pathway, the parents took an active role in forming and leading social groups (e.g., Cub

Scouts) or other activities in which their child could participate. For instance, Jamie mother as well as Mike's mother felt the social isolation of living in neighborhoods without many children. Both mothers had their sons participate in neighborhood Boy Scout meetings to further their lagging social skills. These parents all wanted to find a place where their child could participate in a positive setting.

The third life strategy pathway tried in this study was that of direct advocacy for the child with dyslexia. By far the most vocal advocates in this study were the mothers of Jim, Jamie and Kimm. Sometimes the responsibility for being an advocate for the child however fell to a grandparent. In this study, Amy's grandmother tried to advocate at the local school level for her granddaughter but was, in the grandmother's words, "ignored" because she was not the child's biological parent.

Some additional life strategies related to the three major approaches identified above were also written in the Parent Reflection Journal. These included advice and suggestions from, for example, Penny's mother to other

parents to "have a child tested early and get help. Never give up." Amy's grandmother suggested that parents "work with your kids" and to “encourage the grandparents to read with them." However Steve's mother suggested, "this too will pass. Don't be concerned about what you think other people think about you. No one else is going to be an advocate for your child." Finally, Kimm's mother suggested that parents "be patient, but persistent. Get all the help you can as early as you can! Don't give up; be forceful if necessary."

Life Strategies from the Children

In the present study, the life strategies that the dyslexic children often used to cope with their dyslexia matched their perception of how they themselves felt they learned best.

Kimm, whose stated learning preference was "to hear it," used a tape recorder to tape the teacher's lessons and instructions so that she could play back the teacher's lesson or instructions for clarification. Two other auditory learners, Tim and Steve, felt that both a life strategy and a classroom survival skill that worked for them was to read printed information out loud and then repeat (sub-vocalize)

the information or directions to themselves whenever they felt there was a need.

Other children identified a learning model, which included the simultaneous use of multiple learning preferences. That is, their life strategy was to "see, hear and do" at the same time. For example, Billy's life strategy (used both inside and outside the classroom was to discuss information by talking it over with friends. Billy also used a visual learning strategy, which was to "think in my mind and see and draw pictures". Finally, the use of technology (either with audiotape or with computers) was also mentioned by the children as a life strategy for living and coping with dyslexia.

Some of the children interviewed also mentioned specific "organizational strategies" that were especially helpful to them, such as "lining up all my books in my book bag" and having "a different color notebook for different subjects."

Thus, while their life strategies were predominately classroom survival skills (since most of their waking hours were spent in classrooms) the children also used some of the

same strategies in their life outside of school. For these children with dyslexia, learning strategies thus became life strategies. They represented a means for survival both inside and outside the classroom environment.

Chapter 5

Conclusions

This chapter contains a discussion of the study findings. It also explains some of the implications of the study, and gives recommendations for future research.

Introduction

The concerns voiced by the parents and the children in the present study relate to the work of Kubler-Ross (1969), Harwell (2001) and Osman (1982). Here we can make several points of comparison in the situations of family with children with dyslexia and families with children having other special needs.

Family Dynamics of Dyslexia: The Cycle of Despair

The five stages of grief identified in Kubler-Ross (1969) are the stages of denial, anger, depression, bargaining, and acceptance/hope. Harwell (2001) renames these grief stages as emotional stages and applied them specifically to an educational setting. Harrwell (2001) identified five stages of predictable parental feelings when parents first learn of their child's difficulty at school.

Harwell's (2001) five stages of predictable parental feelings are the stages of (a) shock/denial; (b) anger/guilt/blaming; (c)resignation; (d) depression; and (e) acceptance. The work of Osman (1982) also provides some insights into as to how and why the stages of grief identified by Kubler-Ross (1969) impact terminally ill children and their families.

The parents in this study indicated various representations of the Kubler-Ross grief stages as well as their counterpart in the Harwell stages as they retold their own child's story. The Kubler-Ross grief stage of anger was directly expressed by three of the parents interviewed, however most of the parents' anger was generally manifested as frustration and specifically directed at the school.

All of the parents interviewed expressed examples of one or more of the Kubler-Ross's (1969) stages of grief (denial, anger, depression, bargaining, acceptance/ hope) or a comparable emotional stage (shock/denial; anger/guilt/blaming; resignation; depression; acceptance) from Harwell's (2001) work.

The results of the present study about children with dyslexia and their parents also find a parallel in Osman's (1982) study of terminally ill children and their families Osman states "it is understandable that parents resent a child's learning disability to some extent. Somehow, the image of the ideal child never includes a handicap of any kind. (p.45) Thus, in the case of both chronic physical illness and learning challenges, it can be suggested that parents in both cases are confronted with a child who is somehow "marred" and they struggle to come to terms with this situation.

In the present study, the reports of the children reacting to their dyslexia largely expressed by the children as emotional responses that could be expressed by label such as anxiety/nervousness; anger; and bargaining/hope. (Cf., Kubler-Ross, 1969; Harwell, 2001) The particular "stage" or emotional response also uniquely manifested itself in each child's case. Many children readily told of their feelings about dyslexia, but some of the children were less forthcoming about it. This is consistent with the work of Harwell (2000), Feldman (2000) and Hartwig (1984), all of

whom take special note in their studies to state that the intensity and durations of emotional reactions will vary with each individual and may or may not be voiced by the individuals.

Table 5-1 Comparison of Kubler-Ross (1969) Grief Stages and Harwell (2001) Parental Feelings/Reaction Stages

Kubler-Ross (1969) Grief Stages/ Emotional Stages	Harwell (2001) Parental Feelings/ Reaction Stages
Denial	Shock/Denial
Depression	Anger/Guilt/Blaming
Anger	Resignation
Bargaining	Depression
Acceptance/Hope	Acceptance

Further, it appears that the linear model of the Kubler-Ross grief stages does not apply to the family stories of the children with dyslexia in this study. For

example, the grief stages illustrated a cyclic, rather than a linear pattern or timetable following the yearly educational cycle as the child progressed through their school career. In other words, the child's struggle (as well as their families' struggles) did not follow the predictable linear time sequence stages from denial to hope, which might make these struggles eventually "correctable." Rather, the grief stages, when applied to the Family Case stories here showed a yearly, cyclic pattern. The "correctable" nature of the difficulty was never resolved since the child and the family was continually confronted with both academic and social challenges. Thus, they became mired during the school year in one or more of the grief stages.

This pattern began again with the start of a new academic year and repeated itself. In a continual cycle of frustration and despair as efforts to address the child's learning difficulties continually began anew. Each year, many parents and children thought that things would be different. Parents in the present study remained generally hopeful (one of the last emotional stages in the work of Harwell, 2001 and Kubler-Ross, 1969) that the next year

would be different for their child- that next year would be better (more positive) schooling experience. But most of the time, they were not. As the parents and the children told their stories, it became clear that each year or even each day could be one where the difficulties experienced by the child-and therefore the family members- would be experienced as the shattering force of an earthquake or as the mild but continual jolts of speed bumps.

It thus became clear, as the parents and the children told their stories, that the sometimes stormy clouds of dyslexia would remain a part of their lives and that the much hoped for sun at the end of the rainbow indicating that indeed the storm of dyslexia had finally passed, would be elusive for the parents as well as for the children.

Breaking the Cycle:
Obtaining Resources and Hope

Living with dyslexia was thus a daily struggle for the parents and the children in the present study. Some, however, did identify attempts with the help of outside resources to break through this cycle of despair surrounding dyslexia. The following four themes found in the present

study related to the literature on coping with dyslexia will be explored here: a) early identification b) finding and area in which to excel c) breaking the isolation of dyslexia for the child and the family and d) accommodating for the challenges of dyslexia in daily life.

Early Identification

A majority of the children in the present study were identified with dyslexia at the end of the first grade. This is consistent with Harwell's (2001) point that, although there is much emphasis on identifying dyslexia in children at a very early age, it is usually not recognized until the child is in kindergarten or first grade. According to Harwell (2001), observant teachers note that these children seem "out of step" when viewed in context with other children. This too is also consistent with the findings in the present study.

Finding an Area in Which the Children Can Excel

Parents in the present study seemed to experience particularly conflicting emotions when attempting to accommodate for their child's dyslexia. This finding is consistent with the work of Hurford (1998) who noted that

although parents do experience conflicting emotions concerning a child with dyslexia, most parents still search for an area where their child might be "leading the pack" rather than always trying to catch up to his/her peers. The parents of the children in the present study were often actively searching for ways to encourage any recognized or potential talent they saw in their child. For example, parents in this study encouraged physical activities (football, soccer, and gymnastics) musical activities (band) and social outlets for the children (friends, Boy Scouts).

In eight of the ten families in the present study, the parents tried to achieve a balance between the academic difficulties experienced by the child and positive outlets for social activities (e.g. Scouts, swim team, football, soccer, and singing activities), which could involve both the family and the dyslexic child. Parents reported that such outlets helped to break the isolation that dyslexia sometimes imposes on the child and the family.

As also noted in the present study, during some of the child's school years, parents were quick to blame the

teachers or the school for student non- success. (Cf., Hurford, 1998). Additionally, parents experienced difficulties in dealing with both the reality and the chronic nature of the child's dyslexia, and its long-term effects on the family and the child. This last finding confirms Dowanna's (1995) own personal experience in raising her child who had dyslexia.

When the children in this study were asked about how dyslexia or having difficulty reading affected them and the family, they responded by expressing feelings of nervousness, feeling "woozy" or "frozen," being angry, and/or "faking it" (pretending to follow along and know what was going on, but really not feeling confident or really knowing what was being read). Although they did not use sophisticated terminology or scientific language, these children could sometimes articulate the emotions within the family concerning their learning difficulties. This finding from the perspective of the children in the present study provides additional confirming evidence for Hartwig's (1984) comparisons between a family's reactions to a physical diagnosis of a family member and the reactions to learning

disabilities diagnosis, specifically dyslexia, in a family member.

Accommodating Daily for the Challenges of Dyslexia

The children in the present study spoke volumes about understanding and accommodating for their dyslexia in their daily life. Eight of the children could give actual daily life accommodation strategies they used at school. These accommodation strategies appeared to be "learning style" specific (kinesthetic, auditory, visual or tactile) depending upon the strength areas for each of the children. The children also mentioned some helpful individual "organizational strategies."

Both the "learning" and the "organizational" accommodation strategies that the children in the present study identified parallel the findings of Feldman (2000) and of Hurford (1998). Both of these researchers provide confirming evidence in their many detailed case studies that self-understanding for the child is paramount. Children need to understand what has been getting in the way of their success. By understanding their difficulties or limitations,

the children then, by trial and error, can ultimately find what will work for them.

The most frequently mentioned problem identified by the parents in this study was school difficulties (either academic challenges or social challenges) encountered by their dyslexic children in their educational environments. According to the parents, the specific type of school difficulty experienced varied with the child's year in school. For example, school difficulties in the child's early grades could be the expectation of learning the letters of the alphabet or the pressure to commit to memory the steps of a one, two, three or four step division problem experienced in the later elementary grades.

When speaking about their own daily life experiences with dyslexia, the children in the present study likewise spoke of their difficulties in academic studies such as spelling, reading and math. This evidence corroborated with the "school difficulties" theme identified by the parents. Emotional consequences to the children of their dyslexia were also present and were most frequently expressed by the

children in terms of three recurrent themes: nervousness, anxiety and "faking it."

The life strategies that the children used to cope with their dyslexia matched the child's perception of how they themselves learned best (learning style preference). The children's life strategies were predominately classroom survival skills. However, they also used some of the same strategies (learning strategies as well as organizational strategies) to cope with their dyslexia in their life outside of school.

In fact, the present study revealed that both the parents and the children in this study developed many different ways of living with dyslexia. These strategies were as varied as the individual children and family members themselves. Many parents, for example, encouraged their child's natural abilities and talents in sports or encouraged their child's creative talents in the field of art. The parents also looked for social outlets (i.e. Boy Scouts) for their child. A common reaction reported by the parents of the children with dyslexia was the parent's <u>own</u> difficulty and frustration with the school.

Often this frustration led parents to become advocates for their child at their child's school. Parents who advocated on behalf of their child with dyslexia were often the important link between the child's learning difficulties and the help that the child needed to receive. This advocacy on the part of the parents included such actions as finding a learning situation where the child could progress or explaining to the child and other family members how dyslexia impacted each of the members of the family unit.

Both parents and children experienced a similar pattern of frustration as a consequence of the child's dyslexia. For both groups, this frustration manifested typically in a cyclic pattern. That is, both parents and children felt they were always "starting over" at the beginning of each school year or with each new academic or social skill that the child attempted.

Recommendations for Further Research

The present study has yielded a wealth of information that can be used both as informative individual case study data and also as themes within a group of case studies. Based on the findings of the present study, several

recommendations for further research can be made here. These recommendations are:

A follow-up to the present study could be conducted with the original study participants for the purpose of recording additional life strategies and accommodations used by the children and their parents as they make accommodations for the children's dyslexia as the children grow older. With the addition of technology, the use of the “instant message” computer capability could further enhance the information from the children or their parents.

Further comparison studies could be undertaken to focus on a possible causal relationship between children's learning style preferences and children's accommodations for their dyslexia.

A quantitative instrument consisting of different scales for children's use could be developed so that the children would be able to respond through the scale about how they felt about their dyslexia. Measurement of this variable could thus be standardized and subsequently used both in clinical and classroom settings.

A larger (overview/comprehensive) study at the elementary level (Grades K-5) could be conducted to identify learning strategies and life accommodations made by children with the identified disorder of dyslexia so that additional empirical evidence could be added to the literature.

A study could be conducted of those in the educational, medical and the psychological profession who themselves have dyslexia in order to see how their approaches to teaching and treating children with dyslexia may be enhanced or influenced by their own experience and perspectives.

Conclusions

The findings of the pilot study as well as the findings of the present study strongly suggest that first-person accounts of elementary-aged children and their families need to be given a place in all of the scientific communities that study dyslexia. Recording and researching the ongoing daily experiences of children with dyslexia will open the door to a view of the many struggles that these children face on a daily basis. The children's understanding of their dyslexia and the accommodations they make for it is an important but missing area in the literature. Providing an

outlet for the missing voices of the elementary-aged children and their families in the research process should encourage better communication among all the professions especially interested in the study of dyslexia: the educational, medical, and psychological communities. Such critical communications among these different groups are the slender threads that are elements of common ground, which can bind the educational, medical and psychological communities together in a proactive effort in the battle to illuminate the often hidden reality of dyslexia.

The present study further also shows that the research literature in all three of these fields needs to be expanded to include the impact of the diagnosis of dyslexia on the family unit as well. The sharing of life strategies used by both parents and children is important to understanding the life-long impact of dyslexia. This point once again underscores the "critical chasms" that currently exist between the educational, medical and psychological fields that study the disorder of dyslexia.

Often the unrecognized oversimplification about the disorder of dyslexia and the subsequent impact on the

individual family members causes much confusion among all of those dedicated to helping the child with dyslexia. There may exist possible misinterpretation of information by the key individuals (teachers, doctors, and psychologists) who work with the children that are diagnosed with dyslexia as well as their families. This may cause many questions to go unanswered.

There are many unanswered questions that still linger concerning dyslexia and the impact of dyslexia on the child and the family. The present study shows us that it is only in continuing to ask the questions and to speak with the families and the individuals (even elementary-aged children) living daily with dyslexia that dyslexia can be more readily understood and will not forever remain a hidden, shadowy, and often misunderstood, secret shame.

APPENDIX A: COVER LETTER SENT TO SUBJECTS

You are invited to participate in a confidential study concerning families raising children with reading difficulties. As a teacher and former Reading Specialist with great interest in what can be learned especially from the families and the students with reading difficulties, I am conducting this study for my doctoral dissertation at the University of Maryland College Park. My research is being supported by The Reading Center.

Your participation in this study is voluntary. The answers that you provide in your interviews are anonymous and will be kept strictly confidential. You may withdraw from the study at any time. At the conclusion of the study, all interview forms will be destroyed.

I anticipate that the interview will take no more than one hour to complete. I hope you will be willing to schedule the interview at the time of your child's tutoring sessions. If this is not possible, then a time and place of your convenience can be arranged. Another option is a phone interview which can be conducted at a time convenient to you if that is your preference.

Summary results of the study will be shared with The Reading Center,Inc. If you have any questions at all concerning the interview, you may call the phone numbers listed below between the hours of 9:00 A.M. to 11:30 A.M. Please leave a message and your call will be returned. Please call either:

1. Ms. B. Devilbiss
10 West 14th Street
Frederick, MD 21701
(301) 663-0224

Mrs. Lavonne Radonovich
The Frederick Reading Center, Inc.
2785 Lynn Street
Frederick, MD 21702
(301) 662-1051

Your help and cooperation in agreeing to be interviewed is greatly appreciated.

Sincerely,

(Ms.) Bonnie Devilbiss

APPENDIX B: INFORMED CONSENT FORM

PROJECT TITLE Life Stories and Life Strategies of Parents and their Children with Dyslexia

I state that I am over 18 years of age,in good physical health, and wish to participate in a program of research being conducted by Urith Devilbiss at the Graduate School, University of Maryland, College Park, Department of Curriculum and Instruction.

The purpose of the research is to record the daily life strategies used by children with dyslexia and the daily life strategies used by the parents as they accommodate daily for the dyslexia of the child.

The procedures involve two interviews, an initial interview and a follow up interview with the child and a separate initial and follow up interview with the parents of the child. The initial interviews and the follow up interviews will be a month apart.

The choice of a booklet to write their reflection thoughts or an audio tape to record their reflection thoughts will be given to the parents and the child at the time of the initial interviews. The booklets and audiotapes will be collected at the follow up interviews. All information collected in the study is confidential, and my name will not be identified at any time.

I understand that this research is not designed to help me personally, but that the investigator hopes to learn more about the daily accommodating strategies used by children with dyslexia and the daily accommodating strategies used by the parents who are raising a child with dyslexia.I understand that I am free to ask questions or to withdraw from participation at any time without penalty.

Dr. Neil Davidson Department of Curriculum and Instruction College of Education 2226 G H.R.W. Benjamin Building University of Maryland College Park, MD 20742-1175 (301) 405-3147

Signature of Participant Date _____

APPENDIX C: INFORMED CONSENT FOR A MINOR

PROJECT TITLE Life Stories and Life Strategies of Parents and their Children with Dyslexia

I state that I am over 18 years of age, in good physical health and wish to have my minor child participate in a program of research being conducted by Urith Devilbiss at the Graduate School, University of Maryland, College Park, Department of Curriculum and Instruction.

The purpose of the research is to record the daily life strategies used by the children with dyslexia and the daily life strategies used by the parents as they accommodate daily for the dyslexia of the child.

The procedures involve two interviews and a reflection journal. An initial interview and a follow up interview will be scheduled with the parents and a separate initial and follow up interview will be scheduled with the child. The initial interviews and the follow up interviews will be a month apart. The written or audio taped reflection journals will be collected at the follow up interview. All information collected in the study is confidential, and my name or my child's name will not be identified at any time.

I understand that this research is not designed to help my child personally, but that the investigator hopes to learn more about the daily life strategies used by the children with dyslexia. I understand that I am free to ask questions or to withdraw my child from participation at any time without penalty.

Dr. Neil Davidson Department of Curriculum and Instruction College of Education 2226G H.R.W. Benjamin Building University of Maryland College Park, M.D. 20742-1175 (301) 405-3147

_____

_____

Signature of Participant Parent Date

APPENDIX D:INFORMED CONSENT FOR AUDIO TAPING OF INITIAL PARENT AND CHILD INTERVIEWS AND FOLLOW UP PARENT AND CHILD INTERVIEWS

PROJECT TITLE Life Stories and Life Strategies of Parents and their Children with Dyslexia

I state that I am over 18 years of age, in good physical health and wish to have myself and my minor child participate in a program of research being conducted by Urith Devilbiss at the Graduate School, University of Maryland,College Park, Department of Curriculum and Instruction.

I state that I give permission for myself and my minor child to be audio taped during the initial and follow up interviews that will be a part of this study. All information collected in the study is confidential, and my name or my child's name will not be identified at any time.

I understand that this research is not designed to help myself or my child personally, but that the investigator hopes to learn more about the daily life strategies used by the children with dyslexia and the daily life strategies used by the parents who are raising a child with dyslexia.

I understand that I am free to ask questions or to withdraw myself or my child from participation at any time without penalty.

Dr. Neil Davidson Department of Curriculum and Instruction College of Education 2226G H.R.W. Benjamin Building University of Maryland College Park, MD 20742-1175 (301) 405-3147

_____ _____

Signature of Parent Date

APPENDIX E: Parent Interview

Parent Code _____

BACKGROUND INFORMATION:

NAME _____

ADDRESS_____

CITY_____ STATE _____

ZIP CODE _____

General Questions:

1. HOW MANY FAMILY MEMBERS ARE CURRENTLY LIVING IN YOUR HOME? _____

2. HOW MANY OF THESE FAMILY MEMBERS ARE CHILDREN? _____

3. HOW MANY OF THESE CURRENT FAMILY MEMBERS ARE EXTENDED FAMILY MEMBERS SUCH AS AUNTS, UNCLES, GRANDPARENTS?_____

4. HOW MANY CHILDREN IN YOUR FAMILY COME TO THE READING CENTER FOR TUTORING? _____

5. HOW OFTEN DO YOU BRING _____ TO
CHILD'S NAME
THE READING CENTER FOR TUTORING?
_____DAY/DAYS PER WEEK ____ DAY A MONTH

Demographic Information:

6. THE CHILD ATTENDING THE READING CENTER LIVES WITH-

a.)MOM AND DAD b.) MOM ONLY c.) DAD ONLY

d.)OTHER _____

7.EDUCATION LEVEL

MOTHER- a.) SOME SCHOOLING _____

b.) HIGH SCHOOL GRADUATE _____
c.) SOME COLLEGE _____
d.) COLLEGE GRADUATE _____
e.) ADVANCED DEGREE(S) _____
FATHER- f.) SOME SCHOOLING _____
g.) HIGH SCHOOL GRADUATE _____
h.) SOME COLLEGE _____
i.) COLLEGE GRADUATE _____
j.) ADVANCED DEGREE(S) _____

k.)MOTHER'S CURRENT OCCUPATION _____

l.)FATHER'S CURRENT OCCUPATION _____

8.)INCOME LEVEL (TOTAL FAMILY INCOME PER YEAR)

aa.)BELOW $10,000 _____
ab.)BETWEEN $10,000 AND $25,000 _____
ac.)BETWEEN $25,000 AND $35,000 _____
ad.)BETWEEN $35,000 AND $50,000 _____
ae.)BETWEEN $50,000 AND $80,000 _____
af.)BETWEEN $80,000 AND $100,000 _____
ag.)OVER $100,000 _____

9. RACE

a.)_AFRICAN AMERICAN __b.) WHITE ___c.)_HISPANIC
d.)PACIFIC ISLANDER e.) OTHER (SPECIFY)

PARENT INTERVIEW
PARENT CODE _____

10.WHY DID YOU SEEK ASSISTANCE FROM THE READING CENTER?

11.WHEN DID YOU FIRST NOTICE _____ DIFFICULTY
CHILD'S NAME
WITH READING?

12.WHO FIRST NOTICED _____ DIFFICULTY WITH
CHILD'S NAME
READING?

Family Story:

13.TELL ME_____ STORY.
CHILD'S NAME

BEFORE BIRTH?

BIRTH?

FIRST 12 MONTHS?

PRESCHOOL YEARS? (AGES 1-5)

EARLY SCHOOL YEARS? (GRADES K-2)

ELEMENTARY YEARS ?(GRADES 1-5)

LAST YEAR'S SCHOOL YEAR?

THIS YEAR'S SCHOOL YEAR AT THIS TIME?

WITH HIS OR HER PEER GROUP(PLAYMATES)

IN THE NEIGHBORHOOD?

AT SCHOOL?

IN OUTSIDE OF SCHOOL ACTIVITIES?
(BOY SCOUTS, GIRL SCOUTS, GYMNASTICS, ETC)

14. Questionnaire:(APPENDIX G)

WE REQUEST THAT PARENTS REVIEW AND CHECK OFF ON THE QUESTIONNAIRE THE CURRENT SERVICES OFFERED BY THE READING CENTER THAT HAVE BEEN HELPFUL TO YOU OR YOUR CHILD OR HAVE NOT BEEN HELPFUL TO YOU OR YOUR CHILD.

APPENDIX F: Parent Interview Data

Question 10. Why did you seek assistance from The Frederick Reading Center?

PI Jim: We saw a advertisement in the newspaper where Lavonne (the Director of The Frederick Reading Center) was speaking. We went to hear her speak. We liked her and we knew she could help us.

PI Penny: No Response

PI Mike: My son was having problems with reading and Math.

PI Billy: Help in study habits. I felt he needed to get them. He'll need them in high school.

PI Nathan: Lavonne the Frederick Reading Center's director) refers children in need of testing to my husband (psychologist). He does her testing.

PI Amy: She wasn't doing anything. She

didn't know her letters. She was interested but didn't know them.

PI Jamie: Very unhappy with school system on requests that had been made for educational testing and placement.

PI Steve: Reading evaluation

PI Kimm: Kimm couldn't do anything on paper. She could doodle on paper but couldn't write. In First grade she had memorized the books but she couldn't read them.

PI Tim: Started with Tim when he was going into Second grade. Tim was eligible for the Dyslexia Project. Nothing was on the report card. Behavior was a problem. Teachers didn't know how to teach him and he was bored.

PI Jeff: The teachers wanted to hold him back in Kindergarten. The teacher felt he was immature. Got Lavonne (the director of the Frederick Reading Center) to work with him.

Question 11: When did you first notice _____

Child's Name

difficulty with Reading?

PI Jim: Before school- when he was a preschooler.

PI Mike: First Grade.

PI Bill: Two years ago in Third Grade.

PI Nathan: October of 1996 when he was a first grader.

PI Amy: First month of First grade.

PI Jamie: Two weeks before the end of First grade. The teacher called me in. They wanted to hold him back. I refused to hold him back.

PI Steve: Entering First grade. He was put into a very fast moving group. He had a hard time adjusting to the pace of the group and the amount of reading required. He was expected to read a 60 page First grade book in one night. His first grade teacher thought because he couldn't keep up with the reading group and his teacher thought he might have a learning disability. He spent 1 to 1 and 1/2 hours each night doing homework. We had him tested at school and tested again independently.

PI Kimm: During First grade. Did testing at end of First grade. Alphaphonics program not available. Kimm was always too old. She was not age appropriate.

PI Tim: When he was going into Second Grade.

PI Jeff: Kindergarten.

Question 12: Who first noticed child's name difficulty with reading?

PI Jim: I did. (Mom) He was real happy to play in the dirt, but I just couldn't get him to learn his letters. And I used every trick in the book to get him to learn them. He had a terrible time. I almost tore my hair out. I did and his Kindergarten teacher did.

PI Mike: His teachers and my husband and I.

PI Billy: I did. (Dad) He had trouble settling down- Reading and doing homework.

PI Nathan: Both of us. He couldn't phonetically spell in First grade.

PI Amy: I did (Grandmother).

PI Jamie: His First grade Teacher.

PI Steve: His First grade Teacher.

PI Kimm: I did (Mother).

PI Tim: I did at the end of first grade.

PI Jeff: His Kindergarten teacher.

APPENDIX G

Frederick Reading Center, Inc. Services Survey

Please check below how helpful each of the FRC, Inc. services listed below has been to you or your child.

How Helpful?

Not Helpful -------→ Extremely Helpful

Tutoring Services in:	1	2	3	4	5	Apply
Reading						
Spelling						
Mathematics						
Expressive language						
listening and/or thinking skills						
cursive writing						
computer skills						
Testing Services in:						
psychological testing						
educational testing						
learning disabilities testing						
attention deficit testing						
learning styles testing						
Other Services of:						
classroom observations						
educational diagnostic consulting						
computer assessment						
liaison between professionals						
parent support system						
ARD teaming representative						
arrangement of accommodations						
Legal assistance						

Are there other services (not listed above) that would be helpful to you or your child?

Appendix H

Frederick Reading Center, Inc. Services Survey
Summary of Data Collected By Number of Responses

How Helpful?
Not Helpful--→ Extremely Helpful

Tutoring Services in:	1	2	3	4	5	Apply
Reading				3	3	1
Spelling				1	2	2
Mathematics			1	2	1	3
Expressive language			3	1	1	2
listening and/or thinking skills			1	3	1	2
cursive writing			1	1	1	3
computer skills			1		1	4
Study skills				2	1	3
Testing Services in:						
psychological testing					1	1
educational testing					2	0
learning disabilities testing					2	0
attention deficit testing					1	0
learning styles testing					3	1
Other Services of:						
classroom observations						3
educational diagnostic consulting					1	2
computer assessment						3
liaison between professionals					1	2
parent support system					2	1
ARD teaming representative					2	1
arrangement of accommodations					1	2
Legal assistance						3

Are there other services (not listed above) that would be helpful to you or your child?

APPENDIX I

Interview Questions for the Child

Attending The Reading Center, Inc.

CHILD CODE:_____

INTERVIEW DATE:_____

INTERVIEWER:_____

PLACE OF INTERVIEW:_____

BACKGROUND INFORMATION:

1. HOW OLD ARE YOU? _____
2. WHEN IS YOUR BIRTHDATE? _____
3. WHAT GRADE ARE YOU IN? _____
4. HOW MANY BROTHERS OR SISTERS DO YOU HAVE THAT LIVE WITH YOU AT YOUR HOUSE?

   _____ NO BROTHERS OR SISTERS (SKIP TO #5)

   _____ BROTHER(S) HIS NAME?_____ AGE? _____

   _____ AGE? _____

   _____ AGE? _____

   _____ SISTER(S) HER NAME?_____ AGE? _____

   _____ AGE? _____

   _____ AGE? _____

5. DO YOU HAVE ANY STEP BROTHERS OR STEP SISTERS

THAT LIVE WITH YOU AT YOUR HOUSE?

_____NO STEP BROTHERS OR STEP SISTERS

(SKIP TO #6)

_____STEP BROTHER(S)

_____STEP SISTER(S)

6. DO YOU HAVE ANY BROTHERS, SISTERS, STEP BROTHERS OR STEP SISTERS THAT LIVE IN A DIFFERENT HOUSE OTHER THAN WHERE YOU LIVE?

YES _____ NO_____

FIRST NAME AGE BROTHER/SISTER

STEP BROTHER/SISTER

_____

_____

_____

7. Can you tell me why do you come to The Reading Center?

8. Tell me about the things a good reader does when they read?

9. How does having difficulty when you read affect you?

10.How do you think having your difficulty with reading affects your family?

11.What activities outside of school can you do well?

12.Is there anything else that you want to tell me about how you live with dyslexia everyday?

Appendix J

Children's Interview Question Data

In addition to the parent interviews, the children themselves were also asked questions using an interview protocol. The key findings from these interviews are presented below.

7. Can you tell me why you come to the Reading Center?

CI Jim: No response

CI Penny: To read and spell

CI Mike: No response

CI Billy: To get better at my skills of reading And writing. To work on my memory.

CI Nathan: Because my mom wants me to. Because you get Skittles. (a candy treat)

CI Amy: She helps me read

CI Jamie: No response

CI Steve: No response

CI Kimm: Reading and Writing

CI Tim: Learning-Reading and Writing

CI Jeff: ABC's and reading

8. Tell me about the things a good reader does when they read?

CI Jim: No response

CI Penny: Sound it out.Look at words very closely.

CI Mike: No response

CI Billy: Scan down the pages and look for the important words. Important words describe the title.

CI Nathan: Not make mistakes. They [good readers] see exclamation marks and it’s like excitement. They read a question like a question.

CI Amy: I sound out words. I mark words. Point out words with my pencil eraser.

CI Jamie: No response

CI Steve: No response

CI Kimm: Follow along the words with their finger.

CI Tim: Read slowly. Sound it out. I break up the word and sound it out.

CI Jeff: Ask my teacher. Sound it[the word] out.

9. How does having difficulty when you read affect you?

CI Jim: No response

CI Penny: I read it. I hope I know it. I follow along.

CI Mike: No response

CI Billy: I get mad.

CI Nathan: It makes me nervous. Dad tells me to leave the anger out.

CI Amy: I feel woozy like I just feel like I'm frozen.

CI Jamie: No response

CI Steve: No response

CI Kimm: I lose my place.

CI Tim: Makes me nervous.

CI Jeff: Makes me mad.

10. How do you think having your difficulty with reading affects your family?

CI Jim: No response

CI Penny: Have me sound it out or have me sound it out a couple of times. Then have me look at

the word. If I don't understand, they [my mom or dad] read it [the word] to me. Often they tell me the word.

CI Mike: No response

CI Billy: No response

CI Nathan: It affects Dad really bad. He wants me to be smarter.

CI Amy: They [my parents] get frustrated and says, "Man somebody better help me."

CI Jamie: No response

CI Kimm: No response

CI Tim: No response

CI Jeff: No response

11. What activities outside of school can you do well?

CI Jim: Football

CI Penny: Swim team

CI Mike: Race cars

CI Billy: Soccer, Football, Basketball

CI Nathan: Soccer, Hockey, Basketball, Baseball

CI Amy: Cartwheels, Jump rope

CI Jamie: No response

CI Steve: No response

CI Kimm: Swim, Girl Scout's,Sing in the Chorus

CI Tim: Kickball,Dodgeball, Baseball, Boy Scouts, Bowling

CI Jeff: Freeze Tag, Boy Scouts

12. Is there anything else that you want to tell me about how you live with dyslexia everyday?

CI Jim: No response

CI Penny: I put my Spelling book in first. I line up all my books in my book bag. I take whatever I need. I have a different color notebook for different subjects.

CI Mike: No response

CI Billy: Sometimes I pause in the middle of a sentence when I don't know what the word is.

CI Nathan: If there us a vowel somewhere else in the word, you take away the vowel. It helps to put things on the board.

CI Amy: No response

CI Jamie: No response

CI Kimm: I use a bookmark when I read.

I work with my mom sometimes on Spelling.

CI Tim: No response

CI Jeff: No response

APPENDIX K

Parent Reflection Questions

1. What does the term dyslexia mean to you?

2. What happened among your family when you realized your child was having problems learning?

3. How did you come to choose the Frederick Reading Center, Inc. to help your child?

4.How have your child's teachers reacted to his or her difficulty?

5. What advice or life strategies can you offer to parents of a child who is experiencing dyslexia?

APPENDIX L

Parent Reflection Question Data

1. What does the term dyslexia mean to you?

PR Parent of Jim: No response

PR Parent of Penny: The ability to see (read) information from left to right.

PR Parent of Mike:That a child has difficulty in learning, retaining, concentrating, etc.

PR Parent of Billy: No response

PR Parent of Nathan: No response

PR Parent of Amy: No Response

PR Parent of Jamie: No response

PR Parent of Steve: No response

PR Parent of Kimm: To me the term dyslexia is a learning disability which hinders a child's ability to read and write. Children who have dyslexia can learn to read and write, but they learn differently than most children.

PR Parent of Jeff and Tim: Children with learning problems.

2. What happened among your family when you realized your child was having problems learning?

PR Parent of Jim: No response

PR Parent of Penny: We seeked help.

PR Parent of Mike: My husband and I wanted to get the school to give him the help required and I wanted to find extra help (tutoring). Goal was to get the help needed so he would enjoy learning and his self esteem would stay intact. We just wanted the best for him. I also sent him for testing.

PR Parent of Billy: No response

PR Parent of Nathan: No response

PR Parent of Amy: No response

PR Parent of Jamie: No response

PR Parent of Stephen: No response

PR Parent of Kimm: I sat down with my child and explained to her that she had dyslexia and that she sees things differently than other

students. I told her that her brain actually works twice as hard as most and that she is very smart. I explained that she would be getting "extra help" at school too. Then I sat down with her father and her three older brother and explained dyslexia and what extra help she would be getting. The boys were very supportive.

PR Parent of Jeff and Tim: We searched for answers to help them learn better.

3. How did you come to choose the Frederick Reading Center, Inc. to help your child?

PR Parent of Jim: No response

PR Parent of Penny: A friend from church.

PR Parent of Mike: Recommendation

PR Parent of Billy: No response

PR Parent of Nathan: No response

PR Parent of Amy: No response

PR Parent of Jamie: No response

PR Parent of Steve: No response

PR Parent of Kimm: The Director has an excellent reputation. She knows all about dyslexia and other learning disabilities. She knows all about different learning styles. She knows how to work with these children and you see immediate results. But she doesn't stop there. She helps support the parent, helps in getting "help" through the school system for the children and she is a constant source of resources and knowledge.

PR Parent of Jeff and Tim: I found a flyer telling about their center on how they could help children.

4. How have your child's teachers reacted to his or her difficulty?

PR Parent of Jim: No response

PR Parent of Mike:Some teachers are responsive. I have made sure I've had ARD meetings at school so they are aware of his problems, and see that they are meeting his needs.

PR Parent of Billy: No response

PR Parent of Nathan: No response

PR Parent of Amy: No response

PR Parent of Jamie: No response

PR Parent of Steve: No response

PR Parent of Kimm: Unfortunately, every year has been different! We have had a great teacher who is willing to do and try anything/ everything for her. We had a teacher who let her slide whenever anything was too tough for her, which really impaired her progress that year. We had a teacher who knew she was dyslexic and helped when I asked or reminded him to. I think he was a good teacher, but untrained for "special" students. This year's teacher is pretty good. She seems to understand her special needs and is willing to help implement her special accommodations.

PR Parent of Jeff and Tim: We had lots of problems with different teachers because they put all their problems on behavior.

5.What advice or life strategies can you offer to parents of a child who is experiencing dyslexia?

PR Parent of Jim: No response

PR Parent of Penny: Have a child tested early and get help. Never give up.

PR Parent of Mike: Use a timer.

PR Parent of Billy: No response

PR Parent of Nathan: No response

PR Parent of Amy: Work with your kids

Get in and start working with your child

Encourage the grandparents to read with them. You have to know what your kids are doing.

PR Parent of Jamie: No response

PR Parent of Steve: This too will pass.

Don't be concerned about what you think other people think about you.

No one else is going to be an advocate for your child.

Know that your child has rights. Education is a right, not a privilege.

PR Parent of Kimm: Be patient, but persistent Get all the help you can, as early as you can! Don't give up, be forceful if necessary.

PR Parent of Jeff and Tim: One thing they need on their side is the Frederick Reading Center, because the school doesn't always have your child's best interest in mind.

APPENDIX M

Reflection Questions for the Children Attending The Frederick Reading Center, Inc.

1. What do you do in school that helps you to learn?

2. How do you learn best?

3. What is a day in school like for you?

4. What school subjects are the easiest for you? Why?

5. What school subjects are the hardest for you? Why?

APPENDIX N

Children's Reflection Question Data

1.What do you do in school that helps you learn?

CR Jim: Use the computer to write

CR Penny: No response

CR Mike: Pay attention. Don't talk.

CR Billy: Think in my mind and see and draw pictures.

CR Nathan: Write it down.

CR Amy: When I read-I sound them (words) out

In Math I use my fingers and counters to do the problem.

I use a computer to practice Math (Path Attack, Number Jumper and Parrot Game).

CR Jamie: No response

CR Steve: Practice saying what I'm supposed to do and how I'm to do it.

CR Kimm: Use a tape recorder to tape the teacher's lessons and instructions.

I have a special teacher and I am pulled out one time a week and we work together.

I read out loud whenever I need to.

CR Tim: I read. I say things (repeat) out loud to myself.

CR Jeff: Use blocks in Math (to help figure out math problems)

Use books to read

Use puzzles (to help learn the letters of the alphabet)

2. How do you learn best?

CR Jim: Write on the computer

CR Penny: No response

CR Mike: Listening

Work on the computer

Keep my eyes on the teacher

CR Billy: By talking it over with my friends

CR Nathan: I usually repeat it to myself about 3-10 times.

CR Amy: Playing and using the computer

CR Jamie: No response

CR Steve: When you do it and practice it a lot and do it right.

CR Kimm: When I hear it

CR Tim: If I see, hear and do it at the same time

CR Jeff: If I hear it and do it

3. What is a day in school like for you?

CR Jim: No response

CR Penny: No response

CR Mike: Tired, hard, good, fun

CR Billy: Boring because we have to sit for 6 hours and 30 minutes. The best part is recess.

CR Nathan: No response

CR Amy: Fun

CR Jamie: No response

CR Steve: No response

CR Kimm: Everyday is hard. Then she listed these subjects Spelling, Math, Social Studies.

CR Tim: No response

CR Jeff: No response

4.What school subjects are the easiest for you? Why?

CR Jim: Math-I always get A's

CR Penny: No response

CR Mike: Math-I don't know why and Language Arts because we do fun stuff like drawing.

CR Billy: Math because I can figure it out in my mind. I can see the numbers in my mind.

CR Nathan: Math because it's fun. You can do it different kinds of ways like singing and jumping.

CR Amy: Computer Lab because its fun to play on the computer.

CR Jamie: No response

CR Steve: Everything except Math. Why? I like words better- they are easy and fun.

CR Kimm: Language Arts (Reading, Spelling, Writing) We work in smaller groups. Work with the Special Education teacher 4 times a week.

CR Tim: Math, because I know the problems real good.

CR Jeff: Reading books because I've learned the words.

5.What school subjects are hardest for you? Why?

CR Jim: Spelling. It is hard to know the letters.

CR Penny: No response

CR Mike: No response

CR Billy: No subject is really hard

CR Nathan: Reading, because it's hard to understand the words because of all the different shapes and sounds.

CR Amy: Reading, Spelling and Math. I have to work hard.

CR Jamie: No response

CR Steve: Math, because sometimes we have to do complicated things like read the story (problem) and you have to do something with it (comprehend what the problem is asking and writing the response).

CR Kimm: Math we are starting division and it is hard to remember the steps.

CR Tim: None, because I'm smart.

CR Jeff: Hard books and Counting-hard to get to 100. I like things in front of me to count.

References

A Parent's Guide to Section 504. Retrieved February 2, 2004, From http://www.schwablearning.org/print_resources.asp?Type=articles&r=777

Abrams,J.C.(1970). Parental dynamics-their role in learning disabilities. The Reading Teacher 23 (8) 751-760.

Definition of Dyslexia by the International Dyslexia Association (IDA). (2003, October 12). Retrieved October 20,2003,from http://www.interdys.org/index

Donawa,W.(1995). Growing up dyslexic: A parent's view. Journal of Learning Disabilities. 26(6), 324-328.

Doleys,D., Cartelli,L., and Doster,J. (1976). Comparison of patterns of mother-child interaction. Journal of Learning Disabilities. 9 (6), 42-46.

Executive Summary of the No Child Left Behind Act of 2001. Retrieved January 30, 2004, from http://www.ed.gov/print/nclb/overview/intro/execsumm.html

Faerstein,L.M. (1981). Stress and coping in families of learning disabled children: A literature review. Journal of Learning Disabilities. 14 (7), 420-423.

Falik,L.H. (1995). Family patterns of reaction to a child with a learning disability: A mediational perspective Journal of Learning Disabilities. 28 (6), 335-341.

Hartwig,L.J. (1984). Living with dyslexia: One parent's experience. Annals of Dyslexia. 34, 313-318.

Harwell, J.M. (2001). Complete Learning Disabilities Handbook. Paramus, N.J.: The Center For Applied Research.

Hennigh, K. (1995). Understanding dyslexia. Westminister, C.A.: Teacher Created Materials, Inc.

Hurford, D.M. (1998) To read or not to read-Answers to all your questions about dyslexia. New York, N.Y.: A Lisa Drew Book/Scribner.

Jones,R.D. (1992). Word muddles: New theories about dyslexia. American Health. 65-69.

Kubler-Ross, E. (1969) On Death and Dying. New York, N.Y.: The Macmillan Company.

Levine,M. (2002) All Kinds of Minds. New York, N.Y. Simon and Schuster.

Marshall, C. and Rossman, G. (1995) Designing qualitative research. Thousand Oaks, C.A. SAGE Publications.

Mauter,T.S. (1984). Dyslexia-My "Invisible Handicap". Annals of Dyslexia. 34, 299-311.

Merriam-Webster's collegiate dictionary (10th ed.), (1996). Springfield, MA: Merriam-Webster.

Osman, B.B. (1982). No one to play with: The social side of school. New York, N.Y.: Random House.

Rodis, P., Garrod, A and Boscardin, M.L. (2001). Learning Disabilities and Life Stories. Needham Heights, MA.: Allyn and Bacon.

Smith, C. and Strick, L. (1997). Learning Disabilities: A to Z. New York, N.Y. Fireside.

Smith, S. (1995). No easy answers: The learning disabled child at home and at school. New York, N.Y.: Bantam Books.

Steward, M. and Steward, D. (1996) Interviewing children about body touch and handling. Chicago, IL: Monographs of the Society For Research In Child Development.

Waggoner,K. and Wilgosh,L. (1990). Concerns of families of children with learning disabilities. Journal of Learning Disabilities. 23 (2), 97-98.

Webster’s II new college dictionary. (2001).Boston, MA: Houghton Mifflin.

Wetter,J. (1972). Parent attitudes toward learning disability. Exceptional Children. 38 (6), 490-491.

Yin, R. (1984). Case study research. Beverly Hills. CA: SAGE Publications.